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Assessing the Strengths and Difficulties of Typically Developing Siblings of Persons Born with Lifelong Disabilities

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Assessing the Strengths and Difficulties of Typically Developing Siblings of
Persons Born with Lifelong Disabilities

by

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Submitted in Partial Fulfillment of the Requirements

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DEDICATION

To Melissa, Wyatt, Wesley, Vivian, and our little “Wombling”.

ACKNOWLEDGEMENTS

Dr. Gold, thank you for the many early morning meetings, advice on navigating the academic landscape, and for the many ways you helped with putting words to ideas.

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Mom and Dad, thank you for the strength you have manifested in the midst of life's difficulties. Your marriage stands as an Ebenezer.

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My wife Melissa, thank you for being an embodiment of Love in the sweetness that is your presence. Such a treasure knowing I am yours and you are mine. I love you.

ABSTRACT

In this study, strengths and difficulties of siblings of persons born with disabilities were quantitatively assessed, based on parental perception, in comparison to national norms. Answers of 148 parents to the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997; Youthinmind, n.d.a.) for children four to seven years old who are siblings of persons born with lifelong disabilities (SPBDs) were gathered and analyzed. The causal-comparative design compared each subscale of the SDQ for SBPDs against their respective norms in the USA for females or males. SPBDs were found to have no statistically significant difference from the norm group on emotional problems, and neither male nor female SPBDs were found to have a statistically significant difference from their norm counterparts in hyperactivity. The male SPBDs were found to have greater reported conduct problems and peer problems than the norm group. The male SPBDs were also found to have lower reported prosocial functioning than the norm group. The female SPBDs were found to have greater reported conduct problems and peer problems than the norm group. The female SPBDs were also found to have lower reported prosocial functioning than the norm group. The final chapter includes an interpretation of the findings along with recommendations.

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LIST OF ABBREVIATIONS

CDC	Centers for Diseases Control
NHIS	National Health Interview Survey
SD	Sibling with a Disability
SDQ.....	Strengths and Difficulties Questionnaire
SPD	Sibling of a Person with a Disability
SPBD.....	Sibling of Person Born with a Disability

CHAPTER 1

INTRODUCTION

Children aged 4-7 who are typically developing, yet who have a biological sibling with a diagnosable lifelong disability from the time of birth represent a unique population. Over time, treatment has moved from the limits of an individual focus to more of a family focus, and the research documented in this dissertation reflects that change in focus. For the purpose of this study, typically developing siblings of persons with disabilities in general are referred to as siblings of persons with disabilities (SPDs) and typically developing siblings of persons born with lifelong disabilities are referred to as SPBDs. Where they are blended, they are referred to as SPDs. The siblings with actual disabilities are referred to as SDs. To clarify, this study excludes siblings of persons with abnormalities resulting from maternal alcohol or drug use when such a cause is specified. The reason for this is that so much of sibling functioning is contingent upon systemic factors of the family (Minuchin & Fishman, 1981; Mandleco, Olsen, Dyches, & Marshall 2003; Whitaker & Bumbery, 2004).

As indicated by Seligman and Darling (2007/2014), social progress has been slower than clinical success when it comes to addressing the massive increase of persons living with disabilities. Seligman and Darling go on to contrast a medical model with a social model. Consider that a medical model may lead to a more individual focus, i.e., helping the SD to live as close to a typical life as possible through the use of interventions from doctors, physical therapists, speech therapists, occupational therapists,

and perhaps a multitude of other professionals. Such an approach can lead to a neglect of the family system in which the SD resides. If tunnel vision ensues, such an isolated approach can cut short even the medically termed goals for the child. A social model considers context and accommodations for the person with a disability. A systemic approach carries a different potential for providing help to an SD. Minuchin (1974/2003), referring to Gasset's 1961 text, *Meditations on Quixote*, typified the problem of a professional helper ignoring context as comparable to an arctic explorer attempting to head northward while traveling upon a faster southerly flowing iceberg.

When considering families of persons born with lifelong disabilities, it is possible that support can be provided so that SPBDs do not become “invisible children” (Naylor & Prescott, 2004, p. 199). Even when it comes to focusing on the SD, parents taking the time to clarify an understanding of the disability with SPDs can help diminish grudges that they may be harboring toward the SD (Seligman & Darling, 2007/2014). Therefore, when considering the families of persons born with lifelong disabilities, aspects of the typically developing siblings warrant some consideration.

Firstly, SPBDs have at least one sibling with a disability from the moment they meet him/her. Secondly, SPBDs (and all family members for that matter) may not be aware of the disability right away. While such naiveté can be difficult given the shock that may arrive with a diagnosis, it can also serve as a buffer against that shock in the early moments or days of getting to know the SD. Nonetheless, when a diagnosis does arrive, the diagnosis itself can be a relief because at least the presenting problem (i.e., What is going on with my brother or sister?) has a name, and classification helps with simplification and order in the mind of a siblings whose speculations about what is going

on and what might happen later can vary far outside the realm of reality, such as thinking the disability is contagious (Siegel & Silverstein, 1994). Siegel and Silverstein also highlighted that children aged 5-11 believe in fairy tales, and SPDs engage in imagining their SD will one day no longer have the disability. McHugh (2003) indicated that SPDs desire specific answers relevant to their age level, thus supporting the notion SPDs fare better when informed than they do remaining naïve long-term. While that much is known, little is known about the strengths and difficulties of SPBDs aged 4-7 years in the USA, as measured by a valid and reliable instrument.

Concern about persons with disabilities and courtesy stigma for family members has been a longstanding issue (Ali, Hassiotis, Strydom, & King, 2012; see also Gospel of John 9:1-2). The USA formerly had a policy of institutionalization of persons with certain developmental disabilities which lasted until JFK's administration intervened to move the nation toward more community-based care (Kennedy, 1963). The intervention helped pave the way for in-home care for persons with disabilities and necessarily involved their family members. The Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA, Pub. L. 97-248), was passed under the Reagan administration and resulted in providing for the healthcare costs of children with severe disabilities in the community rather than through institutionalization, regardless of family income (Catalyst Center, 2012).

Moreover, families of persons with disabilities on the whole are more likely to contend with a low socioeconomic status (Newacheck & Halfon, 1998; Parish, Rose, Grinstein-Weiss, Richman, & Andrews, 2008). Secondly, SPDs may struggle with internalizing unspoken jealousy or resentment over their SD, as author Kate Strohm acknowledges of herself in *Being the Other One: Growing Up with a Brother or Sister*

who has Special Needs (2005). At the same time, SPDs may be developing deep levels of empathy and sensitivity to the needs of others (Mulroy, Robertson, Aiberti, Leonard, & Bower, 2007), likely due to the many opportunities afforded them to practice such strengths. Thus, they may have deep strengths formed collaboratively with deep struggles. Conceptualizing this from a family systems perspective, it is worth noting that “resilience is forged through adversity, not despite it” (Goldenberg, Stanton, & Goldenberg, 2017, p.27).

The potential for a bimodal distribution of strengths and difficulties of SPBDs also warrants consideration. For some SPBDs, their struggles may overshadow their strengths. Indeed, Williams (1997) found through review of the literature for siblings of children with long-lasting health problems that 60% of publications showed heightened potential for problems, 30% did not identify potential for problems, and 10% found a mixture of both beneficial and problematic outcomes.

When under stress, families tend to gravitate toward known modes of functioning (Minuchin & Fishman, 1981). For families dealing with a chronic stressor, without intervention it is conceivable that over time these modes of functioning will not only be practiced regularly but also solidified. For example, if an SPBD takes on an early form of the placater role (Satir, 1972), it may be that the chronic stress in the family serves to support the roles of all family members and thus serves to reinforce the patterns the placater practices so that it becomes a lifelong role for the SPD.

Please see chapter two for a more detailed discussion on SPDs and SPBDs.

Problem Statement

While many studies have been conducted on siblings of persons with disabilities as a whole outside of the counseling field, e.g., journals on intellectual disability (Cunningham, Glenn, & Fitzpatrick, 2000), journals on pediatric psychology (Lobato & Kao, 2005), journals on developmental disabilities (Meadan, Stoner, & Angell, 2010), and journals on nursing (O'Brien, Duffy, & Nicholl, 2009), few have been done within the field of counseling. As noted by Wofford and Carlson (2017) the counseling literature over the past 20 years published eight articles which spoke, at times indirectly, to interventions, activities, or referrals for siblings. Only Bodenhorn and Lawson (2003), and Layne (2007), dealt with interventions specifically related to siblings. Additionally, Lock, Hendricks, Bradley, and Layton (2010) provided information on a supportive activity for a gathering of families of persons with disabilities. Considering that approximately three percent of babies born in the USA each year have a disability (Centers for Disease Control and Prevention; CDC, 2016), greater attention to the needs of their families, including typically developing siblings, may improve service delivery from counselors and open avenues of research for preventive initiatives as well.

Furthermore, while some studies on SPDs have been conducted in locations outside of the USA, such as the UK (e.g., Cunningham, 1996) and Australia (Giallo, Roberts, Emerson, Wood, & Gavidia-Payne, 2014), it remains to be seen whether findings from such studies would hold true in the USA with its varied demographics and multifaceted healthcare system which differs not only by socioeconomic status but also state by state. A major question is how SPBDs fare in terms of strengths and struggles when compared with norms for the same age-range. Do unique strengths indeed

accompany unique difficulties, as measured by a valid and reliable instrument normed for children in the USA? At the time of the study, there was no literature that answered this question specific to SPBDs through the use of an instrument such as the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997; Youthinmind, n.d.a.). Such was the aim of this study.

Nature of the Study

This study employed a quantitative, causal-comparative research design using the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997; Youthinmind, n.d.a.) with SPBDs aged 4-7 years. Due to the differing norms in the USA, the siblings are divided into males and females except for emotional symptoms (in which they remain combined due to lack of significant difference in the norms). The questionnaire about children 4-7 years old was answered by parents. The original research questions and hypotheses for the study are stated below, followed by the revised research questions and hypotheses, due to the nature of the data that could be accessed at the time of the study. Please see chapter three for a more detailed discussion on the nature of the study.

Original Research Questions:

1. Is there a difference between parental perceptions of SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared on emotional problems, as measured by the SDQ?
2. Is there a difference between parental perceptions of male SPBDs 4-7 years of age and the norms for male children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, peer problems, and prosocial behavior, as measured by the SDQ?

3. Is there a difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, peer problems, and prosocial behavior, as measured by the SDQ?

Original Alternative Hypotheses:

1. There is a significant difference between parental perceptions of SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared on emotional problems, as measured by the SDQ.
2. There is a significant difference between parental perceptions of male SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, peer problems, and prosocial behavior, as measured by the SDQ.
3. There is a significant difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, peer problems, and prosocial behavior, as measured by the SDQ.

Revised Research Questions:

1. Is there a difference between parental perceptions of SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared on emotional problems, as measured by the SDQ?
2. Is there a difference between parental perceptions of male SPBDs 4-7 years of age and the norms for male children of the same age-range in the USA when they are compared

simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ?

3. Is there a difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ?

4. Is there a difference between parental perceptions of male SPBDs 4-7 years of age and the norms for male children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ?

5. Is there a difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ?

Revised Alternative Hypotheses:

1. There is a significant difference between parental perceptions of SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared on emotional problems, as measured by the SDQ.

2. There is a significant difference between parental perceptions of male SPBDs 4-7 years of age and the norms for male children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ.

3. There is a significant difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when

they are compared simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ.

4. There is a significant difference between parental perceptions of male SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ.

5. There is a significant difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ.

Purpose of the Study

The purpose of the proposed study was to identify strengths and difficulties of persons 4-7 years of age who are siblings of persons born with lifelong disabilities (SPBDs) that are diagnosable from or prior to birth who are residing in the USA. This exploration was conducted through the administration of a survey containing the Strength and Difficulties Questionnaire (SDQ; Goodman, 1997; Youthinmind, n.d.a.) to parents who provided their perspective on their children who are SPBDs, and comparing those answers to results from the National Health Interview Survey for 2016 (CDC, 2017) and, due to the NHIS no longer inquiring about prosocial behavior, the summary data drawn from an earlier NHIS for SDQ norming (Youthinmind, n.d.b.). This study exists to shed light for counselors of this population so as to aid in the search for strengths at intake as well as potential areas for growth.

Operational Definitions

Children – Persons under 18 years of age.

Conduct problems – For the purpose of this study, the meaning is limited to the definition provided by the author of the SDQ subscale for conduct problems, which is described in chapter three.

Born with – Occurring by the time of birth.

Disability – A medically diagnosable disorder that limits a person from achieving a standard level of functioning. For the purpose of this study, the phrase “born with” often appears with the term “disability” to signify the distinction that if a person is born with a disability, it is diagnosable and said to have occurred by the time of birth, even if symptoms did not manifest immediately after delivery or the diagnosis came later (e.g., with a sensory disability such congenital blindness or deafness). Where there is current uncertainty about the epidemiology of a disorder, it is not included in the category of “born with a disability” (e.g., autism spectrum disorder is not in the “born with” category at this time). Due to the confounding factor of maternal substance use on child functioning, disorders known to be caused by maternal alcohol or drug use (such as Fetal Alcohol Syndrome) are excluded from consideration in this study even though the child is indeed born with the disability. The reason for this is that so much of sibling functioning is contingent upon systemic factors of the family (Minuchin & Fishman, 1981; Mandleco, Olsen, Dyches, & Marshall 2003; Whitaker & Bumberry, 2004).

Emotional problems – For the purpose of this study, the meaning is limited to the definition provided by the author of the SDQ subscale for emotional problems, which is described in chapter three.

Hyperactivity – For the purpose of this study, the meaning is limited to the definition provided by the author of the SDQ subscale for hyperactivity, which is described in chapter three.

Parent – Biological or step father or mother of children who either has primary custody or resides in the home with the children, or both.

Peer problems – For the purpose of this study, the meaning is limited to the definition provided by the author of the SDQ subscale for peer problems, which is described in chapter three.

Prosocial behavior – For the purpose of this study, the meaning is limited to the definition provided by the author of the SDQ subscale for prosocial behavior, which is described in chapter three.

Sibling – Biological full or half brother or sister to another person.

Aspects of the Research Paradigm and Specific Design

Assumptions

The assumptions of quantitative inquiry apply to this study. These assumptions include the epistemological notion that truth exists and though it may not be directly accessible, what is not true can nearly be accessible to within a certain percentage of predictability (i.e., the alpha level is the predicted level at which one can reject the null hypothesis). An additional assumption is that the constructs are normally distributed among the population, thus with a representative sample a reasonable level of objectivity and generalizability is attainable.

The proposed study is causal-comparative. This method of inquiry serves as a connection between descriptive and experimental research, basically examining

participants who possess a specific variable and comparing them to the norm (Borg, 1963). In that sense, a causal-comparative study purports to explain what is known and how to progress without being able to fully explain the past, because some outside factor could be influencing the factors under consideration (Huck, 2009), and any significant finding cannot officially be declared without replication. In keeping with the variable descriptors recommended for non-experimental counseling research (Heppner, Wampold, Kivlighan, 2008) the presence of a sibling born with a lifelong disability is considered a predictor variable, and each subscale score is considered a criterion variable. Covariates would also have been used if assumptions were met for the independent variable not influencing the covariate variable, equal regression slopes, and linearity (Huck, 2009). However, covariates were not used in this study for reasons explained later in this text. The reason for using causal-comparative research in this instance is that the predictor variable is already present and it would be unethical to create it for the sake of research (Lodico, Spaulding, & Voegtle, 2006). Lastly, findings from this study only apply to SPBDs aged 4-7 years, living in the USA, and may not generalize to SPDs of a similar age range even in the USA.

Limitations

Threats to validity for this study include a lack of randomization (because the study was non-experimental), subject selection (it is possible that some participants in South Carolina may be known by the author), other-report (parent report about the child), and participant bias in answering the SDQ. As there is no manipulation of variables involved, the furthest the conclusions can be drawn is to indicate that there seems to be

evidence of particular findings, yet this would only point to a potential cause, not clear proof (Lodico, Spaulding, & Voegtle 2006).

Scope

This study involved use of SDQ subscale scores for parent perspectives of SBPDs 4-7 years of age who are residing in the USA, in comparison national norms on those subscales.

Delimitations

The researcher chose to recruit participants heavily within South Carolina as this is the state in which the researcher has a network of individuals and organizations that could be called upon to participate or recruit participants. The researcher sought to recruit participants through word of mouth and through organizations which serve families of persons born with disabilities such as a family networking organization.

The SDQ was selected over other measures because it has been normed for the USA (Bourdon, Goodman, Rae, Simpson, & Koretz, 2005) and it has sufficient breadth and depth which should aid in the response rate. Furthermore, one study found that mothers of low-risk children preferred the SDQ over the Child Behavior Checklist (CBCL; Achenbach, 1991), the SDQ was better than the CBCL at identifying hyperactivity and inattentiveness, and it has a similar capacity to identify problems of both externalizing and internalizing (Goodman & Scott, 1999).

Significance of the Study

Knowledge Generation

This study served to generate heretofore veiled knowledge in the area of strengths and difficulties for SBPDs. Thus, practitioners can begin exploring the findings with

clients who resemble the sample, and researchers can look to this study as a model for future studies. Furthermore, a view to strengths can lead to social change in that potentially deficit-laden perspectives of SPBDs can be replaced with a view that includes their strengths as co-existing with any difficulties revealed. Moreover, if this study is replicated then a counselor may be able to hypothesize the presence of certain manifestations of strength and difficulty for clients who are SBPDs, as well as use this model for future research.

Professional Application

Decades ago, it was known that SPDs may be more likely to present for counseling than the child with a disability (Poznanski, 1969). The reason it is important to search for strengths at an intake is because it is from strengths that clients grow (Ivey & Ivey, 2007), and often from growth that presenting problems are overcome or at least become manageable. Therefore, if counselors explore clients' strengths at intake, this tactic exhibits a focus on growth rather than mere symptom reduction, aids in the building of the therapeutic alliance, and provides a springboard for delving further into idiomatic strengths of the client/family (Duncan, 2014).

As the therapeutic alliance is said to have a greater effect on outcomes than theoretical approach (Duncan, 2014), an emphasis on building up the alliance should fit with a number of therapeutic models and thus serve to inform the field of counseling at large. As Duncan points out, counselors skilled at building the therapeutic alliance focus on it right from the start.

While child therapists may nod to the finding that behavioral therapy for children outperforms other theoretical approaches (Weiss & Weisz, 1995), they may also

acknowledge this finding is based on statistical significance, not clinical significance. Family systems approaches have also been shown to be efficacious in families dealing with a variety of presenting problems (e.g., see Goldenberg, Stanton, and Goldenberg, 2017, ch. 16). Play therapists come to that modality from a variety of backgrounds and yet are for the most part agreed on helping children through means of play, toys, art, and metaphors. So, regardless of the theoretical approach, the counselor during the intake with a child SPBD might manifest a bit of an “Aha” realization in counseling when lighting upon the discovery the client/identified patient is an SPBD and say something like, “Well I’m willing to bet that you have some real strong parts of you and that you have a certain way of seeing others and the world that could help us work together for you to overcome [insert presenting problem]. I’m also willing to bet that the same things that help make you strong also led to some struggles you may or may not think about much, and we can look at those too. Either way, you and your family can help me know what your world is like, and what their world is like, and we can go from there.”

Counselors equipped with the knowledge gleaned from this study can also have some ready-made points to discuss with families of SPBDs in order to normalize some of their struggles and promote their strengths.

Social Change

As this research is promoted through presentation and publication, the wider world will be made aware of not only the difficulties faced by SPBDs, but also some of their strengths. Thus, parents may find the results useful in considering whether or not to have another child if they already have a child born with a disability. Teachers may find the information useful with regard to engaging SPBDs as well as their families.

Furthermore, policymakers, charity organizations, and non-profits may be better equipped to render funding decisions about support programs such as *Sibshops* (Meyer, Vadasy, & Fewell, 1985; Sibling Support Project, 2015), workshops designed to facilitate connection and support for siblings of persons with disabilities.

Transition Statement

This chapter describes the content of the proposal which was approved and carried out to research parental perceptions of siblings of persons born with disabilities (SPBDs) aged 4-7 years in the USA, in the areas of emotional problems, conduct problems, hyperactivity, peer problems, and prosocial behavior, as measured by the Strengths and Difficulties Questionnaire (SDQ), compared to norms of parental perceptions for males and females of the same age in the USA. It was hypothesized that differences would be found based on group membership. Given the findings discussed in later chapters, counselors can be informed about these areas for SPBDs from the outset, should they or their families present for counseling.

The chapters that follow serve to provide greater details on the study and the results. Chapter two provides a review of related research on siblings of persons with disabilities. Chapter three provides details about the study design. Chapter four provides details about the data analysis. In closing, chapter five provides an interpretation of the findings, implications for social change, as well as recommendations for further action and future study(ies).

CHAPTER 2

LITERATURE REVIEW

This review of the literature provides an explanation of the philosophy behind quantitative research as well as an overview of a systemic perspective on people in context. Afterward, theory specific to causal-comparative research is explored. This is followed by a review of previous studies regarding siblings of persons born with disabilities (SPBDs) as well as siblings of persons with disabilities (SPDs). Literature on SPDs is included due to the dearth of literature specific to SPBDs. Searching concurrent with the writing of this dissertation used PsycARTICLES, Psychology and Behavioral Sciences Collection, PsycINFO, and Social Sciences Full Text (H.W. Wilson) using scholarly (peer reviewed) specifier, subject terms “sibling”, “disability”, and “child”. Note that as of March 13th, 2017, no results were found for 2017. In order to replicate this search, the years of publication must be limited from 2012-2017. The previous studies are divided into sections based on conceptual articles/literature reviews, qualitative studies, and quantitative studies. Lastly, a synopsis of key points for the study is provided along with an overview of the content of remaining chapters.

Philosophy

According to Lodico, Spaulding, & Voegtle (2006), quantitative inquiry is based upon scientific realism which is founded upon positivist thinking. They point out that positivist thinking is often used in physical sciences in the area of measurement (e.g., level of cancerous cells in a body). A main assumption is that reality exists, including

psychological reality, and the composite parts of that reality can be individually and collectively researched so as to understand how they relate to one another. Lodico et al. highlighted an important caveat to be aware of in terms of recognizing the possibility of human error though, so reported results are given in terms of probability. Phillips and Burbules (2000), writing from a postpositivist perspective, criticized a purely positivist approach in their assertion that knowledge is “conjectural” (p. 29) and thus “always subject to reconsideration” (p. 30).

Lodico et al. (2006) further noted that quantitative researchers seek a certain level of confidence in what they find, and they seek to remain detached from participants in attempt to remain objective and free of values and biases which could otherwise influence the study. Lodico et al. further noted that “different persons have different perceptions of reality; however, they [scientific realists] assume that experiences overlap to a large degree and that a good researcher can take these different perceptions into account in providing the best possible explanation of reality” (p. 7).

Central aspects of quantitative inquiry on the topic of strengths and difficulties of children are as follows. Every child exhibits strengths and difficulties. Furthermore, these strengths and difficulties can be defined and measured. For children 4-7 years of age, parents are typically able to report on them via answers to a valid and reliable instrument which operationally defines those constructs.

Theories

Family Systems

From a systemic perspective, strengths exist alongside difficulties and as a duality they influence one another. Furthermore, people are complex and unpredictable on a

micro-level, yet they respond to their environments as well as influence them, and systems influence individuals in manifold ways, especially family systems. These ideas are drawn from Minuchin and Fishman (1981) who applied Arthur Koestler's term "holon" (p. 13) to any person in a family, indicating that the individual cannot be conceptualized apart from the whole. Minuchin and Fishman conceded that it is difficult for persons brought up in Western culture to think in such terms, yet presented a cogent argument as to precisely why this frame of mind is helpful when considering families.

Whitaker's conceptualization of persons went still further in that he mused that there is no individual, rather what we call individuals are actually just "fragments of families" (Whitaker & Bumberry, 2004, p.19). To risk a metaphor, consider that one cannot conceptualize an opposable thumb apart from the hand to which it is attached. Additionally, consider viewing Knoff's (1986/2003) graphical depiction of the ecological approach to conceptualizing persons, which involves multiple overlapping systems beyond just the person and family. Bronfenbrenner's (1994) outline of the ecological approach is a tool which captures the importance of context in understanding human functioning embedded in multiple layers of environment. Bronfenbrenner indicates a variety of systems which affect a person: microsystems (exchanges in which the individual is directly involved, such as family), mesosystems (exchanges which involve part of the microsystem and part of another system which affects the individual, such as family and school), exosystems (e.g., contexts which are outside of direct contact with the individual yet still have an impact, such as parental workplace) macrosystems (broader contexts than the person's microsystem and exosystem but which still have an

impact, such as cultural influences), and chronosystem (e.g., time, historic/hemispheric/global events).

The views described above can be applied to SPBDs. They can be studied on an individual level when bearing in mind the contexts which they occupy will vary, as will the contexts which occupy them (i.e., the ways their contexts may be framed in their minds). Again borrowing from a systemic perspective, the statement that “resilience is forged through adversity, not despite it” (Goldenberg, Stanton, & Goldenberg, 2017, p.27), sums up one way that strengths and difficulties may contribute to the development of SPBDs.

Furthermore, children born with disabilities in the USA are no longer regularly institutionalized. Rather, they stay with their family, which means that the care and raising of these children becomes a family concern. Thus, that concern likely has an effect on the growth of SPBDs. This effect may lead to mixed outcomes for SPBDs, with a sort of bifurcated trajectory leading to unique difficulties as well as unique strengths. An answer to whether or not this is so for SPBDs 4-7 years of age in the USA old had not been quantitatively measured using the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997; Youthinmind, n.d.a.) prior to the current study, which is precisely why it was the focus of the current study. Lastly, this theoretical foundation led to the consideration of parental relationship status as a potential covariate in the analyses, as that is a major part of the family structure in which the children are raised. In terms of the independent variable not influencing the covariate, the data is mixed on this point. Consider that having a very low birthweight infant is associated with a 90% chance of maintaining a marriage within two years as opposed to a 95% chance of maintaining a

marriage within two years when the child does not have a very low birthweight (Swaminathan, Alexander, and Boulet, 2006). However, number of children did not magnify chances of divorce for parents of a child with developmental disability (Namkung, Song, Greenberg, Mailick, & Floyd, 2015). As indicated by Seligman and Darling (2007/2014) regarding their review of the literature in this area, more research needs to be conducted relative to marriages in families of children with disabilities compared to families of children without disabilities.

Quantitative Inquiry

Theories of quantitative studies hold to the concept of scientific realism (Lodico et al, 2006). Lodico et al. further specify that quantitative inquiry uses numbers to illustrate constructs, labeled as variables in research, which are considered real and can be measured though they cannot be seen (e.g., educational attainment). This is all done in an attempt to sort through the causes and effects of various areas of interest. Researchers use instruments which can be summed up numerically, such as questionnaires.

Causal-comparative research is subsumed within a quantitative approach. This method of inquiry serves as a connection between descriptive and experimental research, basically examining participants who possess a specific variable and comparing them to the norm (Borg, 1963). In that sense, a causal-comparative study purports to explain what is known and how to progress without being able to fully explain the past, because some outside factor could be influencing the factors under consideration (Huck, 2009), and any significant finding cannot officially be declared without replication. In keeping with the variable descriptors recommended for non-experimental counseling research (Heppner, Wampold, Kivlighan, 2008) the presence of a sibling born with a disability is considered

a predictor variable, and each subscale score is considered a criterion variable. The reason for using causal-comparative research in this instance is that the predictor variable is already present and it would be unethical to create it for the sake of research (Lodico et al., 2006).

Previous Studies

Previous studies on the topic of siblings of persons with disabilities (SPDs) and siblings of persons born with disabilities (SPBDs) are reported in order of the nature of the study (conceptual articles / literature reviews, qualitative, and quantitative) and then chronological order. Searching concurrent with the writing of this dissertation used PsycARTICLES, Psychology and Behavioral Sciences Collection, PsycINFO, and Social Sciences Full Text (H.W. Wilson) using scholarly (peer reviewed) specifier, subject terms “sibling”, “disability”, and “child”. Note that as of March 13th, 2017, no results were found for 2017. In order to replicate this search, the years of publication must be limited from 2012-2017.

Conceptual Articles / Literature Reviews

Hewitt, Agosta, Heller, Williams, and Reinke (2013) researched information regarding families of persons with developmental disabilities and intellectual disabilities. They recognized the likelihood of SPDs being the eventual caregivers of their SDs. They stated as follows regarding supports for families: (a) family involvement in decision-making comes with an opportunity cost when it may be possible for the SD to self-advocate; (b) no universal definition for family support as it varies depending on the state, and support of the SD is construed by some to be family support; (c) no national database regarding support for families, which makes it difficult to render data-driven

decisions; (d) expanding call for support for persons with disabilities living at home with their families, partially due to increased life-expectancy, and state caps on spending shed light on the view that in-home services may be less expensive than services outside of the home; (e) relying too much on federal Medicaid dollars, with state officials seeking to get resources to people needing in-home support through waivers, with caps on the allocations, and Medicaid is not designed to benefit families but rather the individuals with disabilities; (f) no focus on adult SPDs, some of whom may be primary caregivers to their SDs. Hewitt et al. shed light on the overall state of affairs for families of persons with disabilities, yet they did not utilize a survey and their article focused mostly on adult siblings when writing about SPDs. However, the current study utilized a survey and focused on parent perspectives of SPBDs 4-7 years of age.

Riley and Rubarth (2015) described how a multifaceted approach from healthcare professionals is needed to help the family. The researchers highlighted how babies born with low-birth-weight and severe problems have experienced heightened survival rates due to current medical practices. They also described the effect of having a child with a disability and supports for families of such children. Riley and Rubarth's review of the literature revealed mixed results rather than a monolithic finding regarding families' reactions to having a child with a disability. They mentioned that supporting the parents, emotionally, resulted in better family functioning. However, when it comes to peer support groups for SPDs, they reported the literature shows mixed results. The researchers indicated the following resources as helpful: a medical home, early childhood intervention and involvement in an early head start program for the child with the disability, and supportive peer parents in similar situations. They concluded by

emphasizing how nurses can help parents through reframing and a search for the upside to having a child with a disability. While Riley and Rubarth's study contributes the literature on SPDs, it is a conceptual article for informing practitioners, whereas the current study was causal-comparative with an eye toward generating heretofore veiled information.

Mandleco and Webb (2015) conducted a literature review on perceptions of siblings of persons with Down syndrome or autism. Of 277 articles and two manuscripts, they included 26 articles and the two manuscripts. They included qualitative, quantitative, and mixed-methods articles in their review. They reported emergent themes regarding SPD knowledge about the disability, experiences interacting with others, perception of the disability, affective reactions to the experience, and outcomes regarding behavior and/or personality. They concluded that educating siblings about the disability is a must, siblings of persons with autism had more difficulty interacting with the SD than siblings of persons with Down syndrome, and the former also indicated more peer difficulties as a result of having an SD. SPDs from both groups reported affective reactions on the negative side, such as anger or sadness, and positive affective reactions, such as empathy. Compared to siblings of typically developing children, SPDs from both groups were said to have "better self-concepts" (p. 151), exhibited more caring, kindness, and helpfulness, and took on increased responsibilities in the home. However, they noted that some siblings of persons with autism looked upon the increased responsibility in a negative light. Mandleco and Webb's study is limited in a compounding manner based on the limitations of each article in their literature review. Furthermore, their study involved SPDs rather than being limited to SPBDs, whereas the current study examined SPBDs.

Qualitative Studies

In England, Welch et al. (2012) researched if respite service with SDs had any effect on SPDs. Their participants included 239 parents/caregivers (such as step parents, adoptive/foster parents, or grandparents) and 84 SPDs from 3-19 years of age, who provided answers to open-ended questions about using respite services and the ensuing effects. Their findings revealed that SPDs mostly indicated that respite services were helpful in two ways, i.e., in that respite services provided a cushion of time away from some of the difficult sides of being an SPD while those services simultaneously provided space for reflection on the enjoyable sides of being an SPD. Some SPDs did note difficulty with temporary reprieves though, e.g. having a sense of guilt, or a sense anxiety for their SD being cared for elsewhere. Though Welch et al. studied SPDs from both parent and SPD perspectives, the study was qualitative and it was conducted in England. Thus the current study differs in that it was quantitative, used parent perspectives on SPBDs 4-7 years of age, and the sample was drawn from the USA.

Moyson and Roeyers (2012) examined the quality of life of SPDs in Belgium through the lens of being a sibling of a person with an intellectual disability. Their participants were 50 SPDs from 6-14 years of age from 37 middle-to-high income families of children with profound intellectual disability or intellectual disability and multiple disabilities. They conducted three interviews with participants, focused at first on broad self-report, then concentrated on SPD quality of life, and lastly focused on the meaning of being an SPD. They also used focus groups and member checking interviews, and facilitated the SPDs' exploration regarding quality of life through first describing the construct and showing them a list of 10 factors considered common for quality of life.

The SPDs were also asked to think of other domains for quality of life. Their list ultimately came down to nine items predominantly relative to their interaction with their SDs:

1. Joint activities
2. Mutual understanding
3. Private time
4. Acceptance
5. Forbearance
6. Trust in well-being
7. Exchanging experiences among SPDs
8. Social support
9. Dealing with the outside world (p. 93)

Moyson and Roeyers' study was qualitative, conducted on SPDs 6-14 years of age, and took place in Belgium. However, the current study was quantitative and limited to parent perceptions of SPBDs 4-7 years of age in the USA.

Kao, Romero-Bosch, Plante, and Lobato (2012) conducted a study on the perspectives of Latino SPDs and their parents regarding the SPDs' experiences as siblings of persons with developmental disabilities. The participants consisted of 15 family units, with 17 SPDs, 15 mothers, and one father. The SPDs were 8-14 years of age. The researchers found the typical SPD domains involved communication and desired information regarding the disability, positive and negative aspects in the SPD-SD relationship, limitations on SPD social life, and positive aspects of helping care for the SD. They found the typical parent domains about the SPDs involved explaining the

disability to the SPD, positive and negative aspects of SPD-SD interaction, SPD recognition about being treated differently than the SD, and negative emotions regarding the SD. Though Kao et al. studied SPDs and included parent perspectives, the study was qualitative in nature, limited to Latino siblings, and it was conducted with SPDs 8-14 years of age. However, the current study used a quantitative approach to assessing the responses of parents regarding SPBDs 4-7 years of age in the USA and was not intended to be limited to a particular race or ethnicity.

Graff et al. (2012) researched the views of 23 adolescent SPBDs of persons with Down syndrome and a variety of other health problems. The researchers found that many of the participants stated they would not alter their experience in any way. While they did acknowledge difficult aspects of being an SPBD, they tended to underscore the beneficial aspects of their experience. Their focus was more on the SD's primary diagnosis rather than other health concerns, and they did acknowledge their families were impacted by the needs of their SDs. Furthermore, most acknowledged a belief that their SDs would need to live with a caregiver in perpetuity. Though Graff et al. studied SPBDs, the study was qualitative, conducted on adolescents, and limited to SDs with a target disability and multiple health problems. However, the current study was quantitative, sought the parental perspective on children 4-7 years of age, and was intended to examine a broader range of SPBDs (i.e., the SDs had differing primary diagnoses).

Quantitative Studies

In the context of a Bedouin Arab community in Israel, Manor-Binyamini and Abu-Ajaj (2012) examined the coping of 100 SPDs of persons with developmental disabilities compared to the coping of 100 typically developing siblings. The age range of

the participants was 18-27 years of age, yet the researchers refer to them as adolescents. The researchers compared the responses of the two groups in the areas of self-esteem, stress-perception, and growth related to stress. No significant demographic differences were found between the two groups, and an analysis-revealed no significant differences between the groups on a measure of self-esteem. An analysis on a measure of stress-perception revealed that SPDs had higher levels of perceived stress. Furthermore, analyses on a measure for personal growth revealed between groups differences in the following areas: personal (SPDs scored lower), social (SPDs scored higher), religious/faith (SPDs scored higher). Also, for SPDs an analysis revealed negative correlations between stress-perception and perceived social growth, and stress-perception and perceived religious/faith growth. Though Manor-Binyamini and Abu-Ajaj studied SPDs, they studied persons 18-27 years of age and the study was conducted in a Bedouin community in Israel, so it is uncertain at this time whether their findings would generalize to a population in the USA. Furthermore, the current study was conducted on parent perceptions of SPBDs 4-7 years of age and consisted of a sample drawn from the USA.

Senner and Fish (2012) compared children's perspectives with those of parents on the *Sibling Need and Involvement Profile* (SNIP; Fish et al., as cited in Senner & Fish, 2012). The instrument considers measures in five areas for SPDs: (a) awareness of the SDs' disability, (b) feelings about having an SD, (c) having fun, (d) helping at home and the ensuing burden of doing so, and (e) advocacy for the SD. Using three experiments, they sought to determine how the self-report version compared to the original one which sought parental perception, how easily SPDs 8-14 years of age understood the self-report

version, and compared the perceptions of the children with those of their parents. They correlated scores of 88 parents for the self-report and original version and found that the self-report version was consistent with the intended purpose of the original version. They examined the self-report of six children 8-11 years of age and reported good internal consistency on all scales except helping, and that the scales had increased reliability for older children. Last, they compared the scores of 18 children 11-14 years of age to their parents, consisting of 16 mothers and two fathers, and failed to find a significant correlation on the total scores as well as all subscales except for the Feelings section. When they compared parent and child total profiles, they found no significant difference, so they examined the raw score differences and found that parent and child dyads differed with a top range of 30 points. Thus, they concluded that some parents reported less unease on behalf the SPDs than the SPDs' self-reports revealed, whereas other parents reported greater unease on behalf the SPDs than the SPDs' self-reports revealed. Senner and Fish concluded that more research is needed to compare the two versions, but also that even with the constraints it can be helpful for use by practitioners to use both of them with families. Though Senner and Fish studied SPDs, their instrument had more to do with the dynamics surrounding the relationship with the family and the SD, rather than strengths and difficulties of SPBDs that can be compared with normative data, as was the intent of the current study through use of the SDQ (Goodman, 1997; Youthinmind, n.d.a.).

Giallo, Gavidia-Payne, Minett, and Kapoor (2012) examined the perspectives of 52 Australian SPDs regarding their mental health through use of the SDQ (Goodman, 1997) and compared their answers with the Australian norm data on the SDQ. The SPDs

studied were 10-18 years of age. They found that SPD gender was related to prosocial behavior and used it as a covariate in their analyses, and found through single-factor between-subjects multivariate analysis that there were overall multivariate effects on all the subscales, with exception to the total difficulties subscale. Females scored higher than males on prosocial behavior. The researchers ran one-sample *t*-tests to compare means on each subscale of the SDQ. They found that most SPDs reported mental health within the normal range on all the subscales of the SDQ, though SPDs did report greater emotional problems and behavioral problems than a norm sample. About 20-30% of the SPDs had results revealing an at-risk or clinical range score for overall difficulties, hyperactivity-inattention problems, conduct problems, and peer problems. Additionally, 15% of SPDs were found to be in the at-risk or clinical range for scores on emotional problems and prosocial behavior. When Giallo et al. ran analyses for demographic and disability items potentially related to SPDs' reported mental health problems, they did not find any significant predictors of at-risk or clinical range scores. Though Giallo et al. conducted a study using the SDQ with SPDs, it was conducted using Australian youth, and thus it is not yet known whether the findings would generalize to a population in the USA. Furthermore, they studied persons 10-18 years of age and their study was not limited to SPBDs. However, the current study examined parent perspectives of SPBDs 4-7 years of age in the USA.

Long et al. (2013) examined expression of emotions and emotion communication between siblings and parents of children with intellectual disabilities, comparing a Latino sample with a non-Latino white sample. They highlighted the lack of focus on the cultural backgrounds of SPDs, and cited multiple problems that could ensue due to this

oversight, including that what may be considered helpful by one group could be deemed maladaptive by another group. Long et al. recruited 50 Latino SPDs, the same number of non-Latino white SPDs, and the same number from each culture for matched comparisons. They excluded SPDs who themselves had an intellectual disability or serious medical condition, and criteria for exclusion from the comparison groups included the presence of an intellectual disability or a serious medical illness in any child. The age range for children in the study was 8-15 years of age for target children and their matches, and then each SD or match was 3-18 years of age. After running analyses, they found that SPDs reported somewhat greater difficulty with emotion expression than their matched counterparts. They also found that, no matter the sibling status (SPD or not), difficulty with emotion expression and lower measures of sibling-parent communication were predictive of great internalizing and greater somatic symptoms as well as poor adjustment personally. Last, they indicated that, when it comes to cultural differences in emotion expression and communication, those differences can lead to a heightened potential for problems with emotional adjustment among SPDs who are Latino. The Long et al. study examined communication and expression for children 8-15 years of age, which is older than the target group for the current study (4-7 years of age), and the current study was limited to parent reports about SPBDs.

Goudie, Havercamp, Jamieson, and Sahr (2013) tested parental perception of behavioral and emotional problems for SPDs. Using data from the Medical Expenditure Panel Survey, the researchers limited their study to households with at least two children. They formed a group of 245 typically developing SPDs 5-17 years of age, and 6,654 typically developing siblings in the same age range in homes with typically developing

children. When compared with typically developing siblings, they found that SPDs were reported to have more problematic relationships, more problematic psychological, school, and leisure functioning. At the second period of measurement for the study, they found that for SPDs considered significantly impaired when it comes to functioning the percentage had increased from 16.0% to 24.2%. Goudie et al. concluded that the focus in healthcare is often on the SD, yet they called upon professionals to think about approaches that take into account all members of the family. The study involved SPDs rather than being limited to SPBDs. Also, this study appears to have searched for difficulties but not strengths, whereas the current study searched for both.

In Italy, Cuzzocrea, Larcan, Costa, and Gazzano (2014) researched siblings of persons with low intellectual ability versus typically developing children. They examined 32 families who had two children between 8 and 10 years of age. Of those families, half had a child with low intellectual functioning and half had children without a disability. Compared to siblings of persons without disabilities, their findings included that SPDs had greater difficulties in social skills, except for no difference in aggressive behavior, increased likelihood of avoiding peer communication, greater dysfunctional behavior, and greater likelihood of a depressive reaction to situational difficulty, along with physical dysfunction and the appearance of being more fearful. The tendency to have a depressive reaction was related to difficulty in relating to mothers, whereas avoidance of peers appeared associated with difficulty in relation to their fathers. The latter finding stands in contrast to siblings of persons without disabilities, who had an increased likelihood of aggressive reactions in school if they had difficulty interacting with their fathers. Cuzzocrea et al.'s study utilized a small sample for such a large number of

variables and the study took place in Italy. It is yet to be seen whether any such findings would generalize to a population in the USA, and whether or not the findings would apply to SPBDs, as a number of factors after birth may lead to low intellectual functioning for an SD, all of which was taken into account for the current study.

Among Australian children, Emerson and Giallo (2014) used the SDQ in their investigation of the welfare of SPDs and siblings of persons with longstanding health problems versus siblings of typically developing persons. They also examined if any between-groups welfare differences could be explained by socioeconomic differences. They found that the target group siblings had lower measures for conduct difficulties, emotional difficulties, hyperactivity, and prosocial behavior, but that effect sizes were minor, and they also did not find any decompensation among the target group of siblings over a period from four to five years of age and six to seven years of age. There was a population-based study including 1,232 children in the target group; however they noted that they did not exclude target siblings who had a disability or longstanding health problem (e.g., an SPD who also has his or her own disability). They used regression analyses. In addition to using the SDQ, Emerson and Giallo examined socioeconomic status, financial difficulty, maternal education, neighborhood disadvantage, life experiences, maternal mental health, maternal health, and parenting behaviors. While their study is a large study which includes the SDQ for SPDs and relies on parent perception, it took place in Australia. Thus, it remains to be seen whether such findings would generalize to the USA, which is the setting for the proposed study. Moreover, they did not limit the study to SPBDs, and they did not limit the SPDs to typically developing

SPDs. In the case of the current study, typically developing SPBDs were the target children.

Roper, Allred, Mandleco, Freeborn, and Dyches (2014) examined the association between disability type, difficulty of caring for children, and relationships of siblings. They researched 172 families raising typically developing children or an SPD and SD. They found that mothers of children with autism reported greater childrearing difficulty. Furthermore, compared to mothers of typically developing siblings, mothers of children with Down syndrome and parents of children with numerous disabilities indicated greater positivity in relationships between siblings. Roper et al. concluded that difficulty with childrearing acted as a mediator regarding the association between having a child with autism and positivity between the siblings. Their study examined sibling relationships and related that to a measure about parenting, but it was not exclusive to SPBDs and did not compare the measures against a national norm. However, the current study examined parent reports about SPBDs through use of the SDQ (Goodman, 1997; Youthinmind, n.d.a) and compared the sample with national norms for children in the USA.

Platt, Roper, Mandleco, and Freeborn (2014) addressed the issue of SPD cooperative and externalizing behavior through examining 189 families raising an SD and SPD. Their concern was with the difficulty in raising the SD, parenting style, and relationships of SPDs and SDs. They gathered parent reports for multiple questionnaires, using the SPD closest in age to the SD for the sibling under review. The disabilities for SDs in the study included autism, Down syndrome, physical disabilities, intellectual disabilities, emotional or physical disabilities, health impairment, and orthopedic impairment. They found that authoritative parenting was positively related to cooperative

behavior, whereas authoritarian parenting was positively related to externalizing behavior. Sibling relationships predicted cooperative and externalizing behaviors for SPDs. They concluded that positive relations between siblings could help diminish the effect of caregiver difficulty in raising the SD, and that positive relations between siblings can serve as better predictors for SPDs than some parenting behaviors. Though Platt et al. did study parents' perceptions on social skills of SPDs, they did not limit their study to SPBDs, whereas the current study did that.

In Australia, Allison and Campbell (2015) maintained that the quality of the relationship between siblings has a bearing on psychosocial skill development for the entirety of childhood. They recognized that what few findings exist differ with regard to relationship quality between SPDs and SDs. Allison and Campbell studied maternal views on how the disability affects the relationship between SPDs (closest in age to their SDs) and their SDs. Using a questionnaire online, they compared answers of 41 mothers of SPDs and 48 mothers of typically developing siblings. They discovered a reportedly lower level of warmth/closeness among SPDs and SDs when compared to their typically developing counterparts. They did note a finding that younger children were associated with a greater level of warmth/closeness in contrast to older children. Moreover, when the sibling of the target subject was younger, with or without a disability, a greater level of conflict was reported. While Allison and Campbell's study addresses a parent's perception and children are included in the study, it was done in Australia and it assessed sibling relationships as opposed to parent perceptions of strengths and difficulties for SPBDs. However, the current study was conducted with participants from the USA, it was conducted on parent perceptions of SPBDs' 4-7 years of age regarding their

strengths and difficulties using the SDQ (Goodman, 1997; Youthinmind, n.d.a), and compared the sample with national norms for parental perceptions of children in the USA in the same age range.

Cuskelly (2016) quantitatively studied the sibling relationships and intention to become a caregiver for 39 adult SPBDs and their siblings with Down syndrome in Australia. In examining their relationships with one another in childhood and adolescence, she found that problems in behavior served to predict the warmth of SPBDs' relationship at the time of the study. Neither warmth, current relationship quality, or past relationship quality affected the SPBDs' stated intent to be a caregiver to the person with Down syndrome. While Cuskelly's study provided important information about sibling relationships for SPBDs in Australia, it did not directly address parents' perceptions of the strengths and difficulties of the SPBDs as children, whereas the current study addressed those constructs using the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997; Youthinmind, n.d.a.) for parent reports on children 4-7 years of age, comparing them to norms for the USA.

Transition Statement

Studies on the functioning of SPDs and SPBDs have focused on both strengths and difficulties. Articles on the topic within the past five years ranged from conceptual/literature reviews to qualitative and quantitative articles. Some studies involved parent's perspectives, siblings' perspectives, or both. Many studies of late tended to be quantitative in nature and several studies were conducted using the SDQ (Goodman, 1997; Youthinmind, n.d.a.). However, none of the studies examined the means for the five main subscales on the SDQ (emotional problems, peer problems,

conduct problems, hyperactivity, and prosocial behavior) based on parental perspective for SBPDs in the USA 4-7 years of age compared to means for norms in the USA for children 4-7 years of age. The current study was proposed to do just that through a causal-comparative design. Also, based on the analyses of the quantitative studies, using a threshold of category (or one quite similar) analyzed twice or more in separate studies, omitted if not significant unless findings from other studies offset the lack of significance in a study, one covariate could have been considered for inclusion in the analyses: income level. In terms of the independent variable influencing the covariate, consider that just as with the findings on divorce, findings on income are mixed as well. Overall, children born with disabilities are more likely to be in homes with a low income (Newacheck & Halfon, 1998; Parish, Rose, Grinstein-Weiss, Richman, & Andrews, 2008), yet families of children with Down syndrome (of which this study is inclusive) have been found to have much higher incomes than families of children with other disabilities (Cahill & Glidden, 1996) and, importantly, when income was controlled for in a separate study, the oft-cited Down syndrome advantage for parents was no longer found, leading that researcher to conclude that family income has a greater impact on measures of parent coping than does the child's diagnosis (Stoneman, 2007). All of those findings wrap into a systemic framework for this study, as the factors that affect parents are also understood to affect the children in the home. However, as is explained later in this text, income was ultimately not considered a covariate.

Chapter three contains an explanation of the research design for this study, including a description of the sample, instrument, the analysis used, and ethical steps taken to protect the rights of participants. Chapter four contains the data analysis for this

study. Chapter five provides interpretations of the findings of this study along with implications and recommendations.

CHAPTER 3

METHODOLOGY

This chapter on the methods of the study is separated into seven sections. First, the research design and approach is described. Second, the setting and the intended sample of parent perspectives for siblings of persons born with disabilities who are 4-7 years of age is described. Third, the use of the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997; Youthmind, n.d.a.) to collect parental reports is supported. Fourth, the means of data analysis are presented and supported. Fifth, an explanation of the analyses is described. Sixth, ethical measures to protect the rights of participants are described. Seventh, a brief review of the content of this chapter is provided along with an overview of the content of remaining chapters.

Research Design and Approach

Theoretically, the family system was taken into account for overall SPBD strengths and difficulties, yet it is the SPBD in particular with which the current study warrants concern. The study was quantitative, specifically a causal-comparative design. Glesne (2011) indicates that the point in quantitative research within the framework of logical empiricism or a positivist/postpositivist framework is to simplify data in order to generalize it so that predictions can be made, based on the assumption that the constructs are real and can be measured. As indicated by Lodico, Spaulding, and Voegtler (2006), a causal-comparative study is non-experimental yet it provides a bridge between a correlational study and experimental studies, and the reason for using it is because it

would be unethical to re-create the independent variable in a lab setting. In keeping with the counseling literature for non-experimental studies (e.g., Heppner, Kivlighan, and Wampold, 2008), the independent variable was labeled the predictor variable and the dependent variable was labeled the criterion variable. According to Lodico et al. (2006), the idea is that the predictor variable has an influence on the criterion variable so that when the predictor variable is not present (i.e., the presence of sibling born with a disability) then the criterion variable (i.e., means on the SDQ subscales for parent/guardian report for children 4-7 years of age) will be significantly different.

Furthermore, as discussed in chapter two, none of the studies reviewed have examined the comparison means for the five main subscales on the SDQ (emotional symptoms, peer problems, conduct problems, hyperactivity, and prosocial behavior) based on parental perspective for SBPDs in the USA 4-7 years of age compared to means for norms in the USA for children 4-7 years of age. Thus, this study was designed to pursue that line of inquiry. Emotional symptoms are referenced in research question one and hypothesis one without sex differences because an unpaired *t*-test result showed no statistical difference, based on the norms provided for the SDQ in the USA in this age-range, whereas *t*-tests for the other subscales each showed significant sex differences. Prosocial behavior is listed for separate *t*-tests because there were significant sex differences yet the National Health Interview Survey (NHIS) no longer tracks prosocial behavior (CDC, 2017). However, this is still important from a theoretical perspective, thus for prosocial behavior the *t*-test used the norm summary data from the SDQ website (Youthinmind, n.d.b.). The NHIS survey description states as follows regarding the brief

version of the SDQ: “The 2016 CMB is the short version of the SDQ that was originally fielded in 2002 and 2010–2015”, (CDC, 2017, p. 56). The same document also states:

Major Recodes

The original numbering system of the response categories in the instrument has been modified in the Variable Layout Report for all variables in the CMB section. In order to correspond with the SDQ scoring system detailed in Appendix VII, all variables with original answer codes of 1, 2, 3 in the instrument were changed to 0, 1, 2 in the data file, Variable Layout Report, and Variable Frequency Report; all variables with original answer codes of 1, 2, 3, 4 in the instrument were changed to 0, 1, 2, 3 in the data file, Variable Layout Report, and Variable Frequency Report (CDC, 2017, p.56).

Furthermore, the same document states as follows:

The Short Strengths and Difficulties Questionnaire (SDQ)

In the NHIS, questions CMHMF_1– CMHMF_5 (CMB.020_01.000 to CMB.020_05.000) and CMHDIFF (CMB.030_00.000) make up a brief version of the SDQ. The questions are derived from the parent version of the long Strengths and Difficulties Questionnaire Extended (SDQ), developed and copyrighted by Dr. Robert Goodman, Institute of Psychiatry, London, England (Goodman, 1997, 1999). Questions from the SDQ are used in the NHIS with Dr. Goodman’s permission. The short SDQ, constructed to save time and space in the questionnaire, was added for children aged 4–17 years as a part of a collaborative agreement between NCHS and the National Institute of Mental Health (NIMH) of the National Institutes of Health (NIH). Detailed information on the SDQ can be found in Appendix V of the 2004 NHIS *Survey Description* and on the SDQ website at: <https://www.sdqinfo.org>.

The items in the short SDQ correlate to the subscales in the long SDQ as follows:

- CMHMF_1 (Generally obedient) correlates 0.69 with the long SDQ conduct score.
- CMHMF_2 (Many worries) correlates 0.71 with the long SDQ emotion score.
- CMHMF_3 (Often unhappy) correlates 0.64 with the long SDQ emotion score.

- CMHMF_4 (Gets along better) correlates 0.69 with the long SDQ peer problems score.
- CMHMF_5 (Sees tasks through) correlates 0.72 with the long SDQ hyperactivity-inattention score.

Creating SDQ Scores

In order to score the short SDQ, the response for each item in CMB.020 is assigned a value from 0–2 based on the scale below, and then all values are summed to produce a total score. A total score correlates 0.84 with the long SDQ total difficulties score.

Table V. Score assigned for each response, by item: Short Strengths and Difficulties Questionnaire

Variable Name	Not true	Somewhat true	Definitely true
CMHMF_2, CMHMF_3, CMHMF_4	0	1	2
CMHMF_1, CMHMF_5	2	1	0

(CDC, 2017, p. 105).

For more information about the NHIS using the brief version of the SDQ, see the actual NHIS 2016 Survey Description (CDC, 2017). For this study, the mean of variables CMHMF_2 and CMHMF_3 was used to compute an emotion score, CMHMF_1 was used for the conduct score, CMHMF_4 was used for the peer problems score, and CMHMF_5 was used for the hyperactivity-inattention score. As they are drawn from the full SDQ, the same procedure was applied for the SPBD survey data. The original research questions and hypotheses for the study are stated below, followed by the revised research questions and hypotheses due to the limitations of the data that could be accessed at the time of the study.

Original Research Questions:

1. Is there a difference between parental perceptions of SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared on emotional problems, as measured by the SDQ?
2. Is there a difference between parental perceptions of male SPBDs 4-7 years of age and the norms for male children of the same age-range in the USA when they are compared

simultaneously on conduct problems, hyperactivity, and peer problems, and prosocial behavior, as measured by the SDQ?

3. Is there a difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, peer problems, and prosocial behavior, as measured by the SDQ?

Original Alternative Hypotheses:

1. There is a significant difference between parental perceptions of SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared on emotional problems, as measured by the SDQ.

2. There is a significant difference between parental perceptions of male SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, peer problems, and prosocial behavior, as measured by the SDQ.

3. There is a significant difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, peer problems, and prosocial behavior, as measured by the SDQ.

Revised Research Questions:

1. Is there a difference between parental perceptions of SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared on emotional problems, as measured by the SDQ?

2. Is there a difference between parental perceptions of male SPBDs 4-7 years of age and the norms for male children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ?

3. Is there a difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ?

4. Is there a difference between parental perceptions of male SPBDs 4-7 years of age and the norms for male children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ?

5. Is there a difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ?

Revised Alternative Hypotheses:

1. There is a significant difference between parental perceptions of SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared on emotional problems, as measured by the SDQ.

2. There is a significant difference between parental perceptions of male SPBDs 4-7 years of age and the norms for male children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ.

3. There is a significant difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ.
4. There is a significant difference between parental perceptions of male SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ.
5. There is a significant difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ.

For hypotheses one, four, and five, *t*-tests were the appropriate analyses (if covariates had been included then it would have been appropriate to conduct ANCOVAs, but covariates were not used for reasons explained later in this text). A strict alpha level was called for, given that the comparison was between the means of two groups and additional means were compared. Note that since groups were being compared on a total five variables, a Bonferroni adjustment for an alpha level of 0.05 would have led to an alpha level of 0.01, so a principle of parsimony led to simply use the strict alpha level of 0.01 for the *t*-tests. For hypotheses two and three, MANOVAs were used, given that the comparison was between two groups' profiles of means (if covariates were able to be included then the analyses would have been MANCOVAs, but covariates were not used for reasons explained later in this text). Using MANOVAs for the subscales in those hypotheses rather than multiple univariate *t*-tests served to lower an otherwise highly

magnified risk of a type I error (Stevens, 1992). Thus, the equations for the hypotheses are as follows, first in null form and then in alternative form.

Null hypotheses:

$$H_{01} : \mu_1 = \mu_2$$

$$H_{02} : \begin{pmatrix} \mu_{1\ 1} \\ \mu_{2\ 1} \\ \mu_{3\ 1} \end{pmatrix} = \begin{pmatrix} \mu_{1\ 2} \\ \mu_{2\ 2} \\ \mu_{3\ 2} \end{pmatrix}$$

$$H_{03} : \begin{pmatrix} \mu_{1\ 1} \\ \mu_{2\ 1} \\ \mu_{3\ 1} \end{pmatrix} = \begin{pmatrix} \mu_{1\ 2} \\ \mu_{2\ 2} \\ \mu_{3\ 2} \end{pmatrix}$$

$$H_{04} : \mu_1 = \mu_2$$

$$H_{05} : \mu_1 = \mu_2$$

Alternative hypotheses

$$H_{a1} : \mu_1 \neq \mu_2$$

$$H_{a2} : \begin{pmatrix} \mu_{1\ 1} \\ \mu_{2\ 1} \\ \mu_{3\ 1} \end{pmatrix} \neq \begin{pmatrix} \mu_{1\ 2} \\ \mu_{2\ 2} \\ \mu_{3\ 2} \end{pmatrix}$$

$$H_{a3} : \begin{pmatrix} \mu_{1\ 1} \\ \mu_{2\ 1} \\ \mu_{3\ 1} \end{pmatrix} \neq \begin{pmatrix} \mu_{1\ 2} \\ \mu_{2\ 2} \\ \mu_{3\ 2} \end{pmatrix}$$

$$H_{a4} : \mu_1 \neq \mu_2$$

$$H_{a5} : \mu_1 \neq \mu_2$$

For hypotheses two and three, significance was found using the MANOVAs, thus individual tests were conducted to compare each subscale mean from the SPBDs with the corresponding norm mean.

Setting and Sample

The target population was SPBDs 4-7 years of age in the USA, more specifically reports from parents/guardians of SPBDs who were able to complete questionnaires

about the SPBDs. For the purpose of this study, parents/guardians of SPBDs were recruited within the state of South Carolina and nationally during the fall and winter of 2017-2018. See Appendix B for permission from Youthinmind to use an electronic version of the SDQ, and see Appendix C for paper versions representing both waves of electronic surveys. The sample for the USA norms in the same age-range was already determined by the NHIS 2016 data which was narrowed down to specifications for this study (related to hypotheses one, two, and three) and the summary data for the norms (related to hypotheses four and five). That said, NHIS 2016 sample data used only the brief SDQ, which is drawn from the full SDQ. Thus, only certain questions were used rather than all 25. The purpose of using a more recent national sample for hypotheses one, two, and three, is so that the children in the comparison groups would be contextually closer (e.g., historically/chronologically) to the SPBDs where possible, and because the original norms were only available in the form of summary data so a MANOVA was not possible with that data.

Participants were recruited through email lists for agencies, a website, and private Facebook page postings (See Appendix D for a list) and a school, all of the above serving parents of children with disabilities. Typically developing siblings of persons with delayed diagnoses of disabilities were still eligible so long as the condition was determined to have been present since birth. Siblings of persons with developmental disorders that were not diagnosable at birth (such as autism) were excluded from the study. With the systemic theory of human development in mind (discussed in chapter two), disorders directly attributable to maternal substance use (such as Fetal Alcohol Syndrome and Fetal Alcohol Effect) were excluded from the study as the nature of

antecedent family functioning can have too great a bearing on SPBDs so as to confound the results, which is an ill-advised approach when the predictor variable is known and allows for selectivity. The target organizations for overall recruitment included local therapy clinics, Family Connection of South Carolina (an organization serving families of persons with special needs), a school for persons with special needs, and a blogger for caregivers of children with special needs.

The first wave of participants included recruitment through a private Facebook page and a blog for caregivers of persons with special needs. For those wishing to participate, the survey began with an informed consent page. There was also a section with forced field entry which required the primary diagnosis of the child born with a disability. The first wave of participants was recruited without gift a card offer in November, 2017, resulting in six usable responses. After limited responses, the second wave was recruited in January of 2018, with an expanded network of recruiters and a \$10 gift card offer through Tango Card which could be applied to multiple vendors. The first wave was considered anonymous, but the second wave considered confidential rather than anonymous, due to having to enter email address for the gift card. IRB provided approval prior to each step taken in recruitment strategy. As an example of an agency from which participants were recruited in the second wave, The Therapy Place in Columbia, SC, was sent a sign to post along with a direct link (See Appendix E). This way, participants could scan the quick response (QR) code to be linked directly to the survey. The second wave of recruitment resulted in 142 usable responses. Thus, the total of the two waves resulted in 148 usable responses.

Initially, a tentative estimate of sample size was primarily determined through Cohen's (1992) text *A Power Primer*. For determining sample size, it is efficient to choose the sample size based on the maximum amount needed to suffice for one *t*-test based on medium effect size (e.g., 0.15) with $\alpha = 0.05$. The original minimum sample size intended was 64 for each group. In order to ensure robustness even with unequal sample sizes, Tabachnick and Fidell (2007; citing Mardia, 1971), indicated a sample size of 20 in the smallest cell is sufficiently robust. Pallant (2007) highlights that univariate normality can be checked using descriptive statistics and multivariate normality can be checked through Mahalanobis distances. As the norm group from 2001 already had 2,779 (see below), females 1,321, and males 1,458, this left 64 participants to be recruited for the target group of females and 64 participants to be recruited for the target group of males (groups combined when needed for hypothesis one). As there was no way to determine the precise number of children in the sampling area that fit the target criteria before conducting the study, these sample sizes were considered tentative. However, in the end, 2016 NHIS data was able to be obtained for comparison, so it was used for hypotheses one, two, and three, whereas the earlier data used to norm the instrument is currently available in summary form only, so it was used for hypotheses four and five. Descriptions of the sample size are provided later in this text.

Instrumentation and Materials

The instrument utilized for this study was the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997; Youthinmind, n.d.a.), which is now available in over 40 languages (Youthinmind, n.d.a.). The SDQ is a one-page instrument with 25 questions that can be answered in three ways (not true, somewhat true, certainly true) and

can be completed in about 5 minutes. With the SDQ, Goodman (1997) intended to measure 5 constructs: emotional problems, peer problems, conduct problems, hyperactivity, and prosocial behavior. It represents an improvement over the deficit-based Rutter scales which were used in England and which Goodman had modified and then eventually replaced due to parents also wanting to also speak to their children's strengths (Goodman, 1997). Furthermore, it is preferred by mothers over and above the Child Behavior Checklist (CBCL; Achenbach, 1991), especially mothers of children at low risk of problems (Goodman & Scott, 1999). For validity in the process, Goodman used the strategy used by Achenbach for the CBCL, namely whether or not high scores on the overall problems were associated with engagement in ongoing therapy. On that ground, the instrument was found to be valid.

Bourdon, Goodman, Rae, Simpson, and Koretz (2005) examined SDQ norms and psychometric properties in the USA based on an NHIS study in 2001 with over 9,000 participants in which African-American and Hispanic households were overrepresented. Bourdon et al. found evidence of sound psychometric properties for the instrument within the USA, yet also found that parents in the USA tended to report their children in a slightly more favorable light than parents in the UK (based on the norms from Goodman's 1997 study). Furthermore, for high total difficulties Bourdon et al. found significant differences between boys and girls 4-7 years of age ($N = 2,779$) on the overall measure, but subscales were not addressed by sex in the report. Moreover, Bourdon found that parental parameters for high difficulties shifted to the negative for boys 8-14 years of age and girls 11-17 years of age. Using data from SDQ website (Youthinmind, n.d.b.: <http://www.sdqinfo.org/norms/USNorm.html>), unpaired *t*-tests revealed that the

only significant differences on subscales between males and females in the 4-7 age-range were with conduct problems, hyperactivity-inattention, peer-problems, and prosocial behavior (found through calculator from GraphPad Software, Inc., 2017a, 2017b).

Palmieri and Smith (2007) examined custodial grandparents' use of the SDQ and found that race did not have a significant effect on reports for the SDQ, and found good internal reliability. Hill and Hughes (2007), through construct factor analysis, found the SDQ to pass the test, to be an acceptable fit for both genders, and found good internal reliability, though peer problems and prosocial behavior appear to be closely related. One study from Dickey and Blumberg (2004) questioned the discriminant validity of the SDQ in the USA, concluding that instead of five factors (peer problems, emotional problems, conduct problems, hyperactivity, and prosocial behavior) the instrument in the USA really measures three factors (internalizing problems, externalizing problems, and positive construal). However, Palmieri and Smith (2007) indicated it may be premature to make decisions about the instrument based on Blumberg's results. Youthinmind (n.d.a.) does apparently give some credence to this finding on its webpage (www.sdqinfo.com), sharing that for populations considered low risk the three factors could be an alternative means of measurement worth considering. As the literature on SPDs (of which SPBDs are a subpopulation) indicates mixed results when it comes to assessing risk of mental health problems (Williams, 1997; also see chapter two literature review for more recent studies), this study utilized the original five factors for the instrument.

Definitions of constructs based on SDQ criteria

Conduct problems are construed as externalizing behavior, e.g., a history of frequent tantrums, lack of compliance with authority, conflict with peers, deceit, and theft.

Emotional problems are construed as internalizing behavior, e.g., frequently verbalizing concern over physical maladies, a host of fears and worries, frequently low mood, and worrisome feelings or behaviors in novel settings,

Hyperactivity is construed as excessive psychomotor behavior along with some externalizing behavior, e.g., extremely high level of activity or lack of ability to settle down, consistent fidgeting, lack of sustained focus, lack of forethought, lack of assignment completion.

Peer problems are construed as lack of mutuality with other children and may be considered relational manifestations of internalizing behavior, e.g., habitually isolating self in play, lack of any close companion, disliked by peers, harassed by peers, and being better at relating with adults than with peers.

Prosocial behavior is construed as initiative toward amiable relations with others, e.g., conscientious of others' affective states, caring, generous, nice to those of lesser age, and stepping up to be of service to others.

Data Analysis

If assumptions were met (i.e., about the independent variable not strongly influencing the covariate(s), equal regression slopes, and linearity) and likely covariates based on the literature, including theoretical framework, were able to analyzed with the data, ANCOVAs and MANCOVAs would have been used with the following as covariates: income level and parent relationship status. In the end, there was inadequate data for using ANCOVAs or MANCOVAs because all participants indicated being married and there was apparently erroneous data in the income reporting (see chapter four of this text for details). Thus, for the comparison of means for emotional problems

based on parent/guardian report of SPBDs 4-7 years of age, a *t*-test was used with an alpha level of 0.01 in place of a Bonferroni adjustment, given that the comparison was between the means of two groups. Note that since groups were being compared on a total five variables, a Bonferroni adjustment for an alpha level of 0.05 would have led to an alpha level of 0.01, so a principle of parsimony called for simply using the strict alpha level of 0.01 for the *t*-tests. The same goes for males and females on prosocial behavior, separately. For comparing the profile of means for parent reports on three other subscales of the SDQ for SPBDs 4-7 years of age separated by gender with the corresponding profile of means for USA norms for each gender, MANOVAs were used. The three subscales used in the MANOVAs were peer problems, conduct problems, and hyperactivity. Pending any significant difference found using the multivariate *t*-test, individual tests were run on each subscale to find which one or more showed significant difference. The predictor (independent) variable was the presence of a sibling born with a diagnosable lifelong disability, and the criterion (dependent) variable(s) were the means of separate subscales (where applicable) and the profile of means on the other three subscales of the SDQ, implying at least one mean for a subscale on the SDQ differed for the target group compared to the norm group. Because of the software difficulties encountered through the NHIS website maintained by the CDC (see Appendix F), earlier norm data was not available except in summary form. Furthermore, because the NHIS no longer tracked reports of the prosocial behavior of children, the summary data from the SDQ website (Youthinmind, n.d.b.) based on the norm data was used for the analyses for hypotheses four and five.

Measures to Protect Participants' Rights

In order to protect participants' rights, the proposal for this study was subject to review and approved by the Institutional Review Board of the University of South Carolina (see Appendix A). Additionally, each participant was asked to agree to informed consent. The informed consent included information about the researcher, the University of South Carolina, the purpose of the research, acknowledgement that data would be analyzed in the aggregate but that lists of disorders which include rare diseases may compromise confidentiality (e.g. if only one case existed in the USA at the time of data collection), acknowledgment that any participant may withdraw from the study at any time, and whom to contact in case of questions or concerns about the instrument (this list is based on Creswell, 2009). Furthermore, information was kept secure throughout the process of data collection and results were reported solely in an aggregate form.

Summary and Transition Statement

The SDQ has been demonstrated to be a valid and reliable instrument for assessing multiple characteristics of children 4-7 years of age based on parental perceptions. Furthermore, the SDQ can be conceptualized as assessing three constructs for low-risk children in the USA, but because mixed results have been shown in the literature for assessing risk-levels for mental health problems of SPBDs, the five factor model was used in this study. A *t*-test was performed to assess differences in parental perception of emotional problems between SPBDs and the norm group for the USA drawn from 2016 NHIS data, with an alpha level of 0.01 in place of Bonferroni adjustment, and for the remaining three factors comparable with 2016 NHIS data (conduct problems, peer problems, hyperactivity-inattention) a MANOVA was conducted

comparing males to males for each group, and a separate MANOVA was conducted comparing females to females for each group. Lastly, *t*-tests were performed to assess differences in parental perception of prosocial behavior between male SPBDs and their norm counterparts for the USA based on summary data from the SDQ website (Youthinmind, n.d.b.), and the same was done with females, with alpha level of 0.01 in place of a Bonferroni adjustment in both cases.

Chapter four contains the data analysis for this study. Chapter five provides interpretations of the findings of this study, implications for social concerns, and recommendations for practitioners and researchers.

CHAPTER 4

RESULTS

This chapter is intended to provide information regarding the analyses used to assess the hypotheses based on the research questions put forth in chapter three. First, this chapter presents the revision to the original research questions and hypotheses (to account for difficulties in retrieving comparison data and the way the target and comparison data finally had to be analyzed), the data screening process, followed by the results of the analyses for each hypothesis. To review, the purpose of the study is to identify strengths and difficulties of persons 4-7 years of age who are siblings of persons born with lifelong disabilities (SPBDs) that are diagnosable from or prior to birth who are residing in the USA. This exploration was conducted through the administration of the Strength and Difficulties Questionnaire (SDQ; Goodman, 1997; Youthinmind, n.d.a.) to parents who provided their perspective on their children who are SPBDs, and then comparing those results with national data.

The nature of the currently available data called for using several different sets of data. The target group was SPBDs, combined for hypothesis one and separated by sex for the other hypotheses. The main comparison group was from the National Health Interview Survey (NHIS) 2016 data for hypotheses one through three, and then summary norm data available from the SDQ website (Youthinmind, n.d.b.) for hypotheses four and five. The reason for using a separate comparison group for the final two hypotheses is

because NHIS no longer tracks prosocial behavior on the brief version of the SDQ, yet strengths are still theoretically important to consider in this study.

Revised Research Questions and Hypotheses

Research Questions

1. Is there a difference between parental perceptions of SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared on emotional problems, as measured by the SDQ?
2. Is there a difference between parental perceptions of male SPBDs 4-7 years of age and the norms for male children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ?
3. Is there a difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ?
4. Is there a difference between parental perceptions of male SPBDs 4-7 years of age and the norms for male children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ?
5. Is there a difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ?

Alternative Hypotheses

1. There is a significant difference between parental perceptions of SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared on emotional problems, as measured by the SDQ.
2. There is a significant difference between parental perceptions of male SPBDs 4-7 years of age and the norms for male children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ.
3. There is a significant difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ.
4. There is a significant difference between parental perceptions of male SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ.
5. There is a significant difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ.

Research Tools

Data Collection Instruments

For the study group, a survey was designed in order to capture data using Survey Monkey. The first page of the survey contained informed consent information. The first page was followed by demographic information questions, then the SDQ (approved by

Youthinmind – see Appendix B), and for the second wave of data this was followed by a page requesting an email address in order to send the gift card. Each part of the survey used forced field entry requirements, except for parts requesting specification if “Other” was selected. As a safeguard against duplicate entries, survey monkey only allowed one opportunity to participate for each IP address accessing the survey.

The first wave of participants was recruited through a private Facebook page and a blog for caregivers of persons with special needs. For those wishing to participate, the survey began with an informed consent page. There was also a section with forced field entry which required the primary diagnosis of the child born with a disability. The first wave of participants was recruited without gift a card offer in November, 2017, resulting in six usable responses. After limited responses, the second wave was recruited in January of 2018, with an expanded network of recruiters and a \$10 gift card offer through Tango Card which could be applied to multiple vendors. See Appendix D for a list of locations and recruiters for the survey. The first wave was considered anonymous, but the second wave considered confidential rather than anonymous, due to having to enter email address for gift card. IRB provided approval prior to each step taken in recruitment strategy. As an example of an agency from which participants were recruited in the second wave, The Therapy Place in Columbia, SC, was sent a sign to post along with a direct link (see Appendix E). This way, participants could scan the quick response (QR) code to be linked directly to the survey. The second wave of recruitment resulted in 142 usable responses. Thus, the total of the two waves resulted in 148 usable responses.

Descriptive Data Results

Response Rate

Due to the nature of the data being collected and the manner of collecting the data, an accurate response rate was not trackable. For the first wave of the survey, the link was posted in several places: (1) on the blog www.thislittlemiggy.com, a blog about special needs by a mother of girl with a small stomach and limb abnormality. The link was posted there with an interview with the study author; (2) Club 3-21 private Facebook page (3-21 is in reference to Trisomy 21, the referring to chromosomal abnormality resulting in Down syndrome); (3) Key Changes Therapy Services Facebook page; (4) A school for children with special needs was contacted through a third party, Elizabeth Kiprotich, in an effort to recruit from parents of children who attend the school. For the second wave of the survey which included an offer for a \$10 gift card, the link was posted through the following means: (1) Family Connection SC; (2) The Therapy Place; (3) Blogger for www.thislittlemiggy.com was contacted with an update about the gift card offer; (4) Upside to down private Facebook page; (5) Club 3-21 private Facebook page; (6) Key Changes Therapy, owner Natalie Mullis; (7) Occupational Therapist with Therapeeds, Haylee Mitchell; (8) Beyond EI; (9) Midlands therapy.

Note that after a gift card was offered, there was a certain amount of unusable data that resulted from participation with erroneous answers, as evidenced usually by a number in the place of a name for a disorder. Two unusable responses involved apparent incomplete entries when the participant was likely seeking to indicate an actual disorder. One the one hand this was unfortunate. On the other hand, where there was a listing of

numbers instead of actual disorders it resulted in assisting with identifying unusable data in the study.

A total of 219 responses were indicated for the study. The unusable portion of the data was as follows: 4 responses were blank after the informed consent question, 2 responses did not complete the demographic information and did not even partially complete any SDQ portion of the survey, 64 responses recorded a number in response to the question requiring an answer about the disorder of the SD, and 1 response had an apparently incomplete record of the disorder for the SD. That leaves a remainder 148 usable responses for the study survey.

For the NHIS 2016 data, the following procedures were used to establish a typically developing group of children 4-7 years of age who had a parent provide answers to the brief SDQ. In SPSS, beginning with 11,107 cases, all cases not for children aged 4-7 were excluded. That narrowed it down to 2,356 cases. Then, any cases which involved a direct “Yes” response to the following questions were excluded, where SC appears to stand for Sample Child (variable labels listed in order to differentiate where there is otherwise apparent redundancy of descriptions):

Table 4.1 Exclusionary Variables for NHIS 2016 Norm Group

Variable Name	Variable Label
AMR1R	Ever told SC had an intellectual disability also known as mental retardation
AODD1	Ever told SC had other developmental delay
AMR1RN	SC currently has intellectual disability also known as mental retardation
AODD1N	SC currently has other developmental delay
ADD2	Ever told SC had ADHD/ADD
AMR2R	Ever told SC had an intellectual disability also known as mental retardation
AUTISM	Ever told SC had autism, Asperger's, PDD or autism spectrum disorder
AODD2	Ever told SC had other developmental delay
ADD2N	SC currently has ADHD/ADD
AMR2RN	SC currently has intellectual disability also known as mental retardation
AUTISMN	SC currently has autism, Asperger's, PDD or autism spectrum disorder
AODD2N	SC currently has other developmental delay
CCONDRR1	Ever told SC had Down syndrome
CCONDRR2	Ever told SC had cerebral palsy
CCONDRR3	Ever told SC had muscular dystrophy
CCONDRR4	Ever told SC had cystic fibrosis
CCONDRR5	Ever told SC had sickle cell anemia

CCONDRR6	Ever told SC had diabetes
CCONDRR7	Ever told SC had arthritis
CCONDRR8	Ever told SC had congenital heart disease
CCONDRR9	Ever told SC had other heart condition
SEIZE1	Had seizures, past 12 m
SEIZE2	Had seizures, past 12 m
CBLIND	Blind/unable to see at all
IHMOB +	Impairment/health problem limit crawl/walk/run/play +
IHMOBYR	Impairment/health problem lasted/will last 12+ m

The last two variables in the list were combined for exclusion criteria so that children with short term injuries would not be excluded but any indication that the sample child had an impairment/health problem which limited ability to crawl, walk, run, or play, and would last 12 months or more would lead to exclusion. In addition to the above variables, cases were excluded which indicated that the sample child was “deaf” (for variable name CHEARST1 in NHIS, an individual clarifying answer rather than a straight “Yes” response to a question).

That narrowed it down to 2,061 cases. Then, cases were excluded which did not include a usable answer on any part of the brief SDQ (e.g., the variable indicated something such as refusal to answer, not determined, or unknown). This narrowed it down to 2,018 cases. Upon closer inspection, variables with an indication of “Yes” if ever told the child had a learning disability (variable name LEARNND in NHIS) or if child stuttered/stammered in past 12 months (variable name STUTTER in NHIS) were also excluded. This narrowed it down to 1,974 cases: 984 males and 990 females.

Demographics

Descriptive data are presented first for the target group survey, followed by the NHIS 2016 comparison group demographics, followed by a description of the SDQ norm group for the USA.

Participants in the target survey were 75.7% mothers, 24.3% fathers. Age of participants ranged from 30 – 49 years old, and all participants had at least a college degree. Two participants (1.4%) identified as stay-at-home mothers, whereas the remainder indicated working at least part time, 5.4%, or full-time, 91.9%. All participants were married and represented states from all major regions of the contiguous United States and Hawaii. Number of children in the household ranged from 2 – 4. The average monthly household income question had an extremely wide range of answers and it is assumed that there was a misunderstanding with this question, possibly due to the term “monthly” being in the middle of the prompt rather than at the beginning, thus it is possible some participants mistakenly entered average annual income instead. SPBDs about which answers were rendered were 59.5% female and 40.5% male, ranged from 4 – 7 years of age, 66.2% Hispanic, 33.8% White/Caucasian, and 98.6% of them were biological full-siblings to the siblings with disabilities (SDs). SDs were 67.6% female, 32.4% male, and ranged in age from 11 months or less to 14 years old, and were 65.5% Hispanic, 34.5% White/Caucasian (due to different race/ethnicities of half-siblings), and had a range of disorders. See table 1 for detailed information regarding the target group.

Table 4.2 Survey Demographic Variables*

(*n = 148)

Demographic	Total (n)	Percentage
Participant relationship to the child born with a lifelong disability (SD)		
Mother	112	75.7
Father	36	24.3
Participant relationship to the typically developing (non-disabled) biological sibling (SPBD)		
Mother	112	75.7
Father	36	24.3
Participant age		
30	2	1.4
31	3	2.0

32	10	6.8
33	15	10.1
34	11	7.4
35	13	8.8
36	14	9.5
37	13	8.8
38	27	18.2
39	11	7.4
40	10	6.8
41	5	3.4
42	4	2.7
43	2	1.4
44	4	2.7
47	1	.7
49	3	2.0
Participant highest level of education completed		
Graduated from college	139	93.9
Some master's level courses	6	4.1
Completed master's degree	1	.7
Completed doctoral degree	2	1.4
Participant employment status		
Employed, working full-time	136	91.9
Employed, working part-time	8	5.4
Not employed, NOT looking for work	2	1.4
Other (please specify)*	2*	1.4*
*stay at home mom/homemaker	*1	*.7
*Stay-at-home-mom	*1	*.7
Participant current relationship status		
Married	148	100.0
Participant and children's residence (state/territory)		
Alabama	1	.7
Arizona	10	6.8
Arkansas	1	.7
California	28	18.9
Colorado	3	2.0
Florida	2	1.4
Georgia	2	1.4
Hawaii	2	1.4
Idaho	1	.7
Illinois	8	5.4
Indiana	1	.7
Kansas	2	1.4
Louisiana	1	.7
Maryland	1	.7
Michigan	2	1.4
Mississippi	1	.7

Missouri	3	2.0
Nebraska	1	.7
Nevada	7	4.7
New Jersey	2	1.4
New Mexico	1	.7
New York	4	2.7
North Carolina	2	1.4
Ohio	2	1.4
Oklahoma	2	1.4
Oregon	7	4.7
Pennsylvania	1	.7
South Carolina	11	7.4
Tennessee	3	2.0
Texas	12	8.1
Utah	4	2.7
Virginia	1	.7
Washington	16	10.8
Wyoming	3	2.0
Total number of children living in the home with participant at this time		
2	140	94.6
3	7	4.7
4	1	.7
Participant average monthly household income from any and all sources, in whole dollars [it is assumed that there was a misunderstanding with this question, possibly due to the term “monthly” being in the middle of the prompt rather than at the beginning, thus it is possible some participants mistakenly entered average annual income instead]		
\$3,000 - \$6,999	7	4.7
\$7,000 - \$10,999	15	10.1
\$11,000 - \$14,999	6	4.1
\$15,000 - \$18,999	37	25.0
\$19,000 - \$22,999	24	16.2
\$23,000 - \$26,999	2	1.4
\$27,000 - \$73,999	0	0
\$74,000 - \$85,999	3	2.0
\$150,000 - \$250,999	54	36.5
SPBD Gender		
Female	88	59.5
Male	60	40.5
SPBD Age		
4 years	3	2.0
5 years	14	9.5
6 years	29	19.6
7 years	102	68.9
SPBD race/ethnicity		
Hispanic	98	66.2

White / Caucasian	50	33.8
SPBD relationship to SD		
Biological full-sibling	146	98.6
Biological half-sibling	2	1.4
SD Gender		
Male	48	32.4
Female	100	67.6
SD age		
0-11 months	1	.7
1	2	1.4
2	13	8.8
3	30	20.3
4	5	3.4
5	3	2.0
6	2	1.4
8	3	2.0
9	13	8.8
10	39	26.4
11	24	16.2
12	12	8.1
14	1	.7
SD race/ethnicity [assumed to be different due to the way participants may have conceptualized race/ethnicity of differently for half-siblings, the number of which is within range of the difference for race/ethnicity of SPBDs and SDs, as evidenced by the different race/ethnicities of one set of half-siblings in the individual data]		
Hispanic	97	65.5
White / Caucasian	51	34.5
SD primary diagnosis [note that some participants entered comorbid diagnoses]		
BCS1L [disorder]	1	.7
Blind	2	1.4
Chromosomal abnormality	1	.7
[unspecified]		
Cerebral palsy	7	4.7
Child paralysis sequela	8	5.4
Congenital deafness	12	8.1
Congenital limb deformity	9	6.1
Congenital limbs [disorder]	12	8.1
Congenital malformation(s)	11	7.5
[unspecified]		
Congenital missing limb	8	5.4
Congenital short limb	9	6.1
Down syndrome / Trisomy 21	10	6.8
Down Syndrome, AV canal defect	1	.7
Down syndrome, Hirs[ch]prungs	1	.7

Dwarfism	10	6.8
Genetic disorder [unspecified]	1	.7
Hearing disability	11	7.5
Hemiplegia	11	7.4
Limb deformities [unspecified]	1	.7
Mitochondrial Disease	1	.7
Paralysis	10	6.8
Vision disability [unspecified]	11	7.4

The NHIS 2016 comparison group consisted of 1,974 participants, with a range of respondents' relationship to the sample children. Participants represented each major region of the contiguous United States. Regarding the sample children, 50.2% were female, 49.8 were male, age ranged from 4 – 7 years old, and a variety of races were represented. See table 2 for detailed information on this group.

Table 4.3 NHIS 2016 Demographic Variables*

(*n = 1974)		
Demographic	Total (n)	Percentage
Person's relationship to child (answers of non-parents retained in keeping with SDQ norm data)		
Parent (Biological, adoptive, or step)	1793	90.8
Grandparent	131	6.6
Aunt/Uncle	10	.5
Brother	17	.9
Other relative or other non-relative	23	1.2
Region		
Northeast	293	14.8
Midwest	423	21.4
South	705	35.7
West	553	28.0
Sex of the child		
Male	984	49.8
Female	990	50.2
Age of the child		
4	502	25.4
5	503	25.5
6	509	25.8
7	460	23.3
Race (Hispanic not listed due to subgrouping – see further below for race within Hispanic subgroup)		

White	1479	74.9
Black/African American	270	13.7
Indian (American), Alaska Native	40	2.0
Asian Indian	40	2.0
Chinese	20	1.0
Filipino	29	1.5
Other Asian	47	2.4
Primary race not releasable	21	1.1
Multiple race, no primary race	28	1.4
selected		
(Race within Hispanic subgroup *n = 407)		
(White)	(369)	(90.7)*
(Black/African American)	(14)	(3.4)*
(Indian (American), Alaska	(7)	(1.7)*
Native)		
(Filipino)	(7)	(1.7)*
(Other Asian (See file layout))	(5)	(1.2)*
(Primary race not releasable)	(3)	(.7)*
(Multiple race, no primary race	(2)	(.5)*
selected)		

SDQ Norm Information (used for comparing prosocial scores)

Normative SDQ Data from the USA

The National Health Interview Survey (NHIS) is a multi-purpose health survey conducted by the National Center for Health Statistics, Centers for Disease Control and Prevention, and is the principal source of information on the health of the civilian, noninstitutionalized, household population of the United States. The survey consists of a basic module and variable supplements. The SDQ was included in the 2001 NHIS Supplement. From each family in the NHIS, one sample adult and one sample child (if any children under age 18 are present) are randomly selected. Information on the sample child was obtained from a knowledgeable adult residing in the household. Of the 10,367 children between 4 and 17 in the survey, 9,878 children had complete data on all sections of the SDQ, and this is the sample used in the analyses presented here. A parent (biologic, adoptive, or step) was a reporter for 92% of the SDQ sample. A grandparent was the reporter for 4.4% (Youthinmind, n.d.b.).

Specific to children 4-7 years of age, the SDQ norm information indicates n = 2,779, female n = 1,321, male n = 1,458 (Youthinmind, n.d.b.).

Instrumentation for Study Variables

The instrument for the proposed study was the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997; Youthinmind, n.d.a.), which is now available in over 40 languages (Youthinmind, n.d.a.). The SDQ is a one-page instrument with 25 questions that can be answered in three ways (not true, somewhat true, certainly true) and can be completed in about 5 minutes. With the SDQ, Goodman (1997) purports to measure 5 constructs: emotional problems, peer problems, conduct problems, hyperactivity, and prosocial behavior. It represents an improvement on the deficit-based Rutter scales which were used in England and which Goodman had modified and then eventually replaced due to parents also wanting to also speak to their children's strengths (Goodman, 1997). Furthermore, it is preferred by mothers over and above the Child Behavior Checklist (CBCL; Achenbach, 1991), especially mothers of children at low risk of problems (Goodman & Scott, 1999). For validity in the process, Goodman used the strategy used by Achenbach for the CBCL, namely whether or not high scores on the overall problems were associated with engagement in ongoing therapy. On that ground, the instrument was found to be valid. As described below, NHIS has left off any prosocial variable on their brief version. However, as mentioned above and as is implied via family systems theory, strengths are also important to consider when examining difficulties. That is why the determination was made to compare the SPBD data with the SDQ Norm data separate from the NHIS 2016 data.

NHIS has elected to use a brief version of the SDQ which correlates with scores for the full version, and in so doing NHIS has left off any prosocial variable. The NHIS survey description states as follows regarding the brief version of the SDQ: “The 2016 CMB is the short version of the SDQ that was originally fielded in 2002 and 2010–2015”, (CDC, 2017, p. 56). The same document also states:

Major Recodes

The original numbering system of the response categories in the instrument has been modified in the Variable Layout Report for all variables in the CMB section. In order to correspond with the SDQ scoring system detailed in Appendix VII, all variables with original answer codes of 1, 2, 3 in the instrument were changed to 0, 1, 2 in the data file, Variable Layout Report, and Variable Frequency Report; all variables with original answer codes of 1, 2, 3, 4 in the instrument were changed to 0, 1, 2, 3 in the data file, Variable Layout Report, and Variable Frequency Report (CDC, 2017, p.56).

Furthermore, NHIS states as follows:

The Short Strengths and Difficulties Questionnaire (SDQ)

In the NHIS, questions CMHMF_1– CMHMF_5 (CMB.020_01.000 to CMB.020_05.000) and CMHDIFF (CMB.030_00.000) make up a brief version of the SDQ. The questions are derived from the parent version of the long Strengths and Difficulties Questionnaire Extended (SDQ), developed and copyrighted by Dr. Robert Goodman, Institute of Psychiatry, London, England (Goodman, 1997, 1999). Questions from the SDQ are used in the NHIS with Dr. Goodman’s permission. The short SDQ, constructed to save time and space in the questionnaire, was added for children aged 4–17 years as a part of a collaborative agreement between NCHS and the National Institute of Mental Health (NIMH) of the National Institutes of Health (NIH). Detailed information on the SDQ can be found in Appendix V of the 2004 NHIS *Survey Description* and on the SDQ website at: <https://www.sdqinfo.org>.

The items in the short SDQ correlate to the subscales in the long SDQ as follows:

- CMHMF_1 (Generally obedient) correlates 0.69 with the long SDQ conduct score.
- CMHMF_2 (Many worries) correlates 0.71 with the long SDQ emotion score.
- CMHMF_3 (Often unhappy) correlates 0.64 with the long SDQ emotion score.
- CMHMF_4 (Gets along better) correlates 0.69 with the long SDQ peer problems score.
- CMHMF_5 (Sees tasks through) correlates 0.72 with the long SDQ hyperactivity-inattention score.

Creating SDQ Scores

In order to score the short SDQ, the response for each item in CMB.020 is assigned a value from 0–2 based on the scale below, and then all values are summed to produce a total score. A total score correlates 0.84 with the long SDQ total difficulties score.

Table V. Score assigned for each response, by item: Short Strengths and Difficulties Questionnaire

Variable Name	Not true	Somewhat true	Definitely true
CMHMF_2, CMHMF_3, CMHMF_4	0	1	2
CMHMF_1, CMHMF_5	2	1	0

(CDC, 2017, p. 105).

For more about NHIS using the brief version of the SDQ, see the actual NHIS 2016 Survey Description (CDC, 2017). For this study, the mean of variables CMHMF_2 and CMHMF_3 was used to compute an emotion score, CMHMF_1 was used for the conduct score, CMHMF_4 was used for the peer problems score, and CMHMF_5 was used for the hyperactivity-inattention score. As they are drawn from the full SDQ, the same procedure was applied for the SPBD survey data. Note also that in NHIS 2016 data, the scores for CMHMF_1 and CMHMF_5 were not yet reversed in the raw data, so they were reversed in order to be properly compared with the SPBD sample. Furthermore, after building out the norm prosocial data from the summary data for the SDQ norms (Youthmind, n.d.b.), the prosocial scores were calculated in SPSS using the standard instructions for scoring that subscale on the instrument.

Bourdon et al. (2005) examined SDQ norms and psychometric properties in the USA based on an NHIS study in 2001 with over 9,000 participants in which African-American and Hispanic households were overrepresented. Bourdon et al. found evidence of sound psychometric properties for the instrument within the USA, yet also found the parents in the USA tended to report their children in slightly a more favorable light than parents in the UK (based on the norms from Goodman's 1997 study). Furthermore, for high total difficulties Bourdon et al. found significant differences between boys and girls 4-7 years of age ($N = 2,779$) on the overall measure, but subscales were not addressed by sex in the report. Moreover, Bourdon found that parental parameters for high difficulties shift to the negative for boys 8-14 years of age and girls 11-17 years of age. Using data from SDQ website (Youthinmind, n.d.b.: <http://www.sdqinfo.org/norms/USNorm.html>), unpaired *t*-tests revealed that the only significant differences between males and females in the 4-7 age-range were with conduct problems, hyperactivity-inattention, peer-problems, and prosocial behavior (found through calculator from GraphPad Software, Inc., 2017a, 2017b).

Palmieri and Smith (2007) examined custodial grandparents' use of the SDQ and found that race did not have a significant effect on reports for the SDQ, and found good internal reliability. Hill and Hughes (2007), through construct factor analysis, found the SDQ to pass the test, to be an acceptable fit for both genders, and found good internal reliability, though peer problems and prosocial behavior appear to be closely related. One study from Dickey and Blumberg (2004) questioned the discriminant validity of the SDQ in the USA, concluding that instead of five factors (peer problems, emotional problems, conduct problems, hyperactivity, and prosocial behavior) the instrument in the USA

really measures three factors (internalizing problems, externalizing problems, and positive construal). However, Palmieri and Smith (2007) indicated it may be premature to make decisions about the instrument based on Blumberg's results. Youthinmind (n.d.a.) does apparently give some credence to this finding on its webpage (www.sdqinfo.com), sharing that for populations considered low risk the three factors could be an alternative means of measurement worth considering. As the literature on SPDs (of which SPBDs are a subpopulation) indicates mixed results when it comes to assessing risk of mental health problems (Williams, 1997; also see chapter two literature review for more recent studies), this study utilizes the original five factors for the instrument.

Data analyses

This section reviews the analyses conducted in pursuit of each research question. Each analysis was performed using Statistical Package for the Social Sciences (SPSS 24). Alpha levels are discussed relative to each analysis.

Assumptions for Statistical Analyses

Hypothesis One. Due to limitations of the comparison data, hypothesis one calls for a *t*-test, with alpha level of 0.01 in place of a Bonferroni adjustment, given that the comparison is between the means of two groups and a conservative approach is desired in examining the results of the analysis. The level of measurement for each of them is a continuous interval scale. However, sampling was not completely random. The observations are assumed to be independent of one another, given the nature of the SPBD survey as well as NHIS data gathering techniques. Normal distribution can be violated as every group is larger than 30 (Pallant, 2007). Levene's test for equality of variances was

not found to be significant for hypothesis one, indicating that assumption for equal variances was met for that hypothesis (Pallant, 2007).

Hypothesis Two. Regarding sample size for hypothesis two, there are a larger number of cases than cells. As there are three dependent variables and the smallest sample size is 60 (SPBD males), the numbers are within range for robustness related to violations of normality, for in order to ensure robustness even with unequal sample sizes Tabachnick and Fidell (2007; citing Mardia, 1971), indicate a sample size of 20 in the smallest cell is sufficiently robust. For the variables used in this analysis, Mahalanobis distance has a maximum of 20.908, yet the critical value for three dependent variables is only 16.27 (Pallant, 2007), indicating there are outliers in the data. Upon inspection, there were only nine outliers out of 1,044 cases so the data was retained without transformation of outliers. Regarding a check for linearity, see figure 4.1. Upon inspecting the relationship between conduct and peer problems, there is an extremely small linear relationship present between the two, $R^2 \text{ Linear} = 0.031$, see figure 4.2. Upon inspecting the relationship between hyperactivity and conduct, there is an extremely small linear relationship between the two, $R^2 \text{ Linear} = 0.061$, see figure 4.3. Upon inspecting the relationship between hyperactivity and peer problems, there is an extremely small linear relationship between the two, $R^2 \text{ Linear} = 0.002$, see figure 4.4. Box's Test of Equality of Covariance Matrices indicated a violation of the assumption of homogeneity of variance-covariance matrices, see table 4.4, yet each group had over 30 cases represented so this is an acceptable violation (Pallant, 2007). Levene's Test of Equality of Error variances indicated that hyperactivity and peer problems both violated the assumption of equality of

variance; see table 4.5, thus a strict alpha level of 0.01 may be used for those variables on the univariate F-test (Tabachnick and Fidell, 2007, as cited in Pallant, 2007).

Hypothesis Three. Regarding sample size for hypothesis three, there are a larger number of cases than cells. As there are three dependent variables and the smallest sample size is 88 (SPBD females), the numbers are within range for robustness related to violations of normality, for in order to ensure robustness even with unequal sample sizes Tabachnick

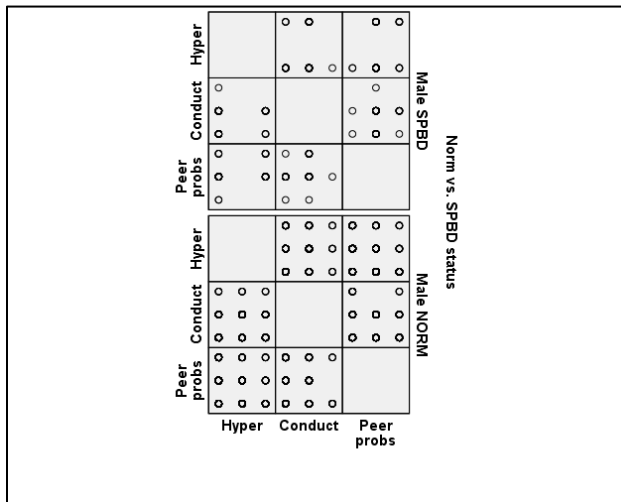


Figure 4.1 Linearity Check for Hypothesis Two

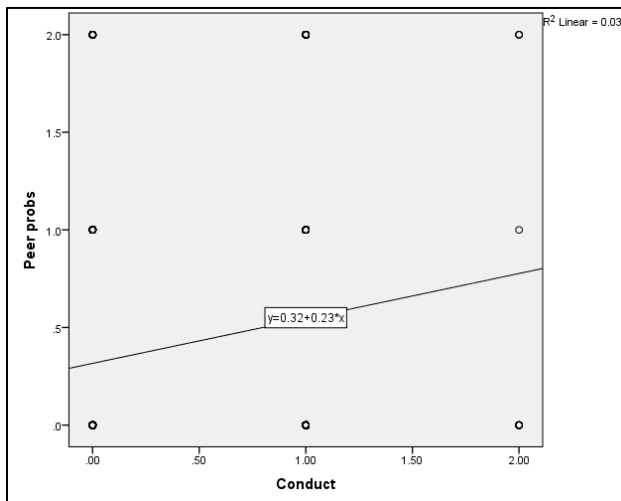


Figure 4.2 Conduct and Peer Problems Linear Relationship for Hypothesis Two

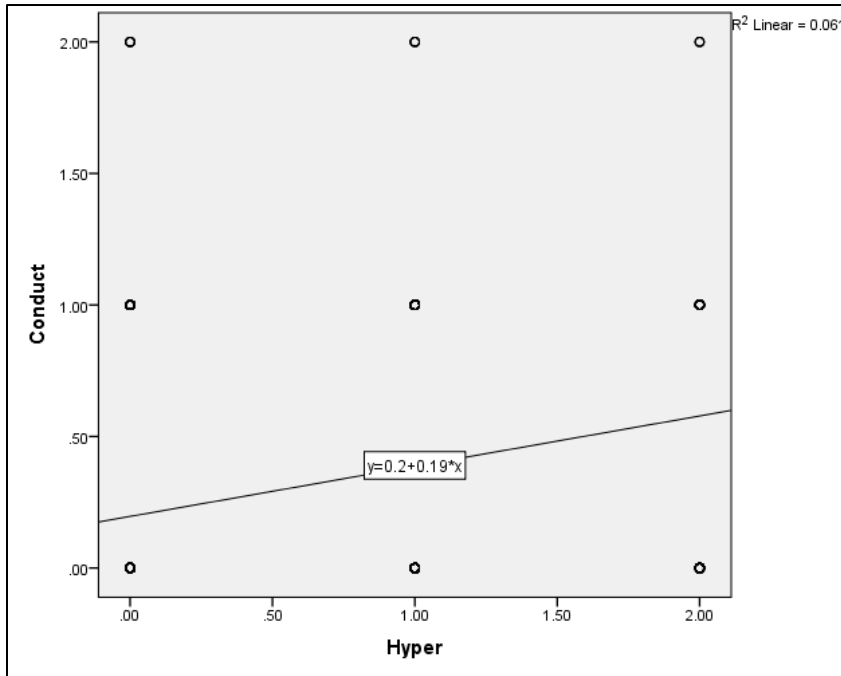


Figure 4.3 Hyperactivity and Conduct Linear Relationship for Hypothesis Two

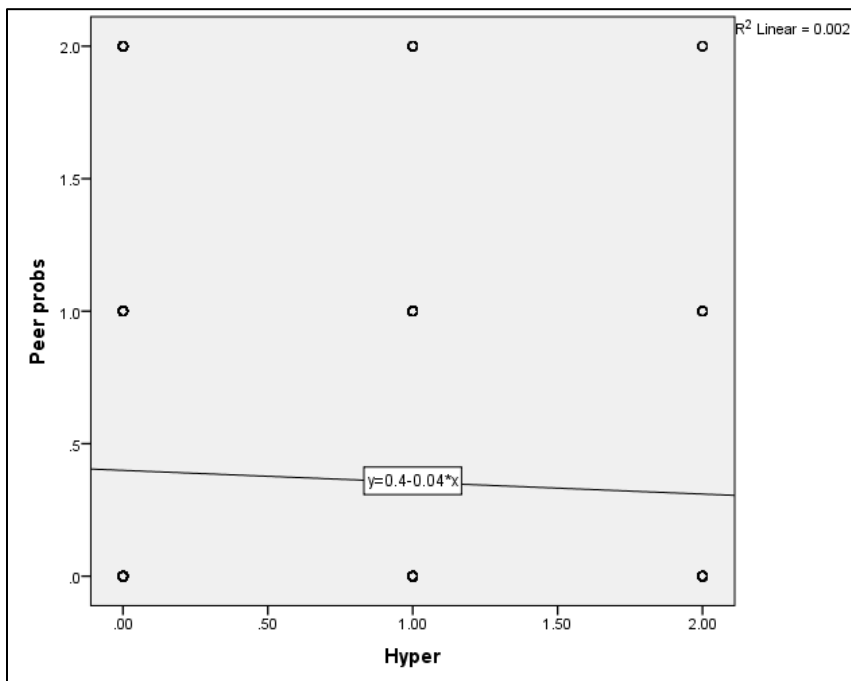


Figure 4.4 Hyperactivity and Peer Problems Linear Relationship for Hypothesis Two

Table 4.4 Box's Test of Equality of Covariance Matrices for Hypothesis Two^a

Box's M	28.733
F	4.700
df1	6
df2	57332.768
Sig.	.000
Tests the null hypothesis that the observed covariance matrices of the dependent variables are equal across groups.	
a. Design: Intercept + NORM_SPBD_STATUS	

Table 4.5 Levene's Test of Equality of Variances for Hypothesis Two^a

	F	df1	df2	Sig.
Hyper	15.608	1	1042	.000
Conduct	.121	1	1042	.728
Peer probs	24.724	1	1042	.000
Tests the null hypothesis that the error variance of the dependent variable is equal across groups.				
a. Design: Intercept + NORM_SPBD_STATUS				

and Fidell (2007; citing Mardia, 1971), indicate a sample size of 20 in the smallest cell is sufficiently robust. For the variables used in this analysis, Mahalanobis distance has a maximum of 19.639, but the critical value for three dependent variables is only 16.27 (Pallant, 2007), indicating there are outliers in the data. Upon inspection, there were only 12 outliers out of 1,078 cases so the data was retained without transformation of outliers. Regarding a check for linearity, see figure 4.5. Upon inspecting the relationship between conduct and peer problems, there is an extremely small linear relationship present between the two, R^2 Linear = 0.018, see figure 4.6. Upon inspecting the relationship between hyperactivity and conduct, there is an extremely small linear relationship between the two, R^2 Linear = 0.070, see figure 4.7. Upon inspecting the relationship

between hyperactivity and peer problems, there is an extremely small linear relationship between the two, $R^2 \text{ Linear} = 0.001$, see figure 4.8. Box's Test of Equality of Covariance Matrices indicated a violation of the assumption of homogeneity of variance-covariance matrices, see table 4.6, yet each group had over 30 cases represented so this is an acceptable violation (Pallant, 2007). Levene's Test of Equality of Error variances indicated that all three criterion variables violated the assumption of equality of variance; see table 4.7, thus a strict alpha level of 0.01 may be used for those variables on the univariate F-test (Tabachnick and Fidell, 2007, as cited in Pallant, 2007).

Hypothesis Four. Due to limitations of the comparison data, hypothesis four calls for a *t*-test, with alpha level of 0.01 in place of a Bonferroni adjustment, given that the comparison is between the means of two groups and a conservative approach is desired in examining the results of the analysis. The level of measurement for each of them is a continuous interval scale. The SDQ norm prosocial score spreadsheet was built out from the norm summary data (Youthmind, n.d.b.) in Microsoft Excel and then imported into SPSS. Note that SPBD sampling was not completely random. The observations are assumed to be independent of one another, given the nature of the SPBD survey as well as norm data gathering techniques. Normal distribution can be violated as every group is larger than 30 (Pallant, 2007). Levene's test for equality of variances was not found to be significant for hypothesis four, indicating that assumption for equal variances was met for that hypothesis (Pallant, 2007).

Hypothesis Five. Due to limitations of the comparison data, hypothesis five calls for a *t*-test, with alpha level of 0.01 in place of a Bonferroni adjustment, given that the comparison is between the means of two groups and a conservative approach is desired in

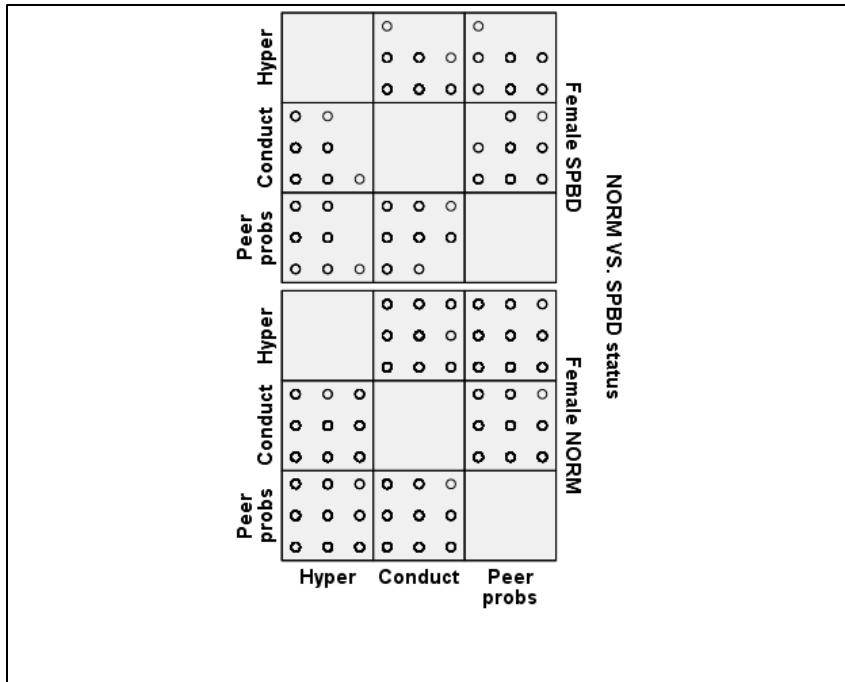


Figure 4.5 Linearity Check for Hypothesis Three

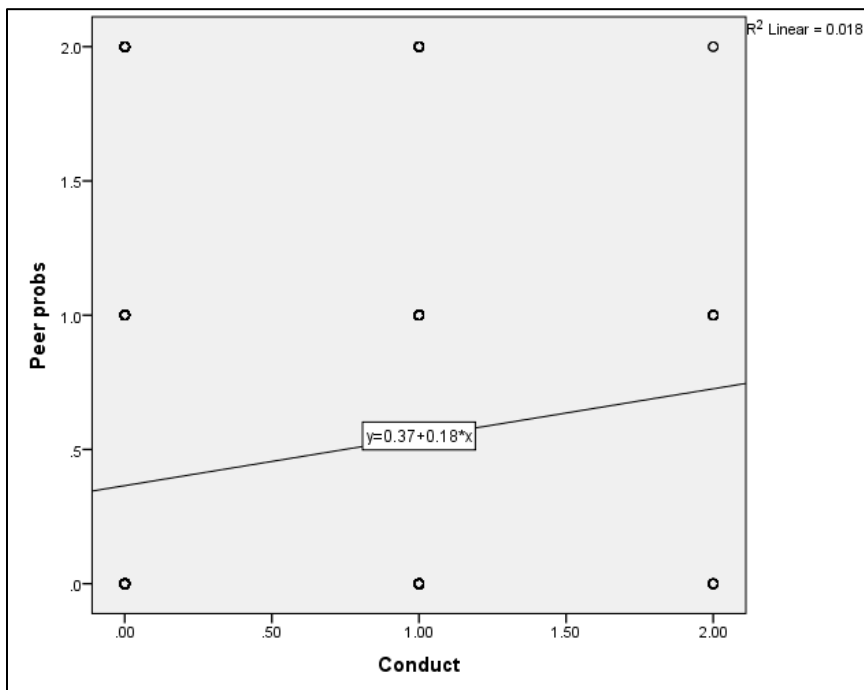


Figure 4.6 Conduct and Peer Problems Linear Relationship for Hypothesis Three

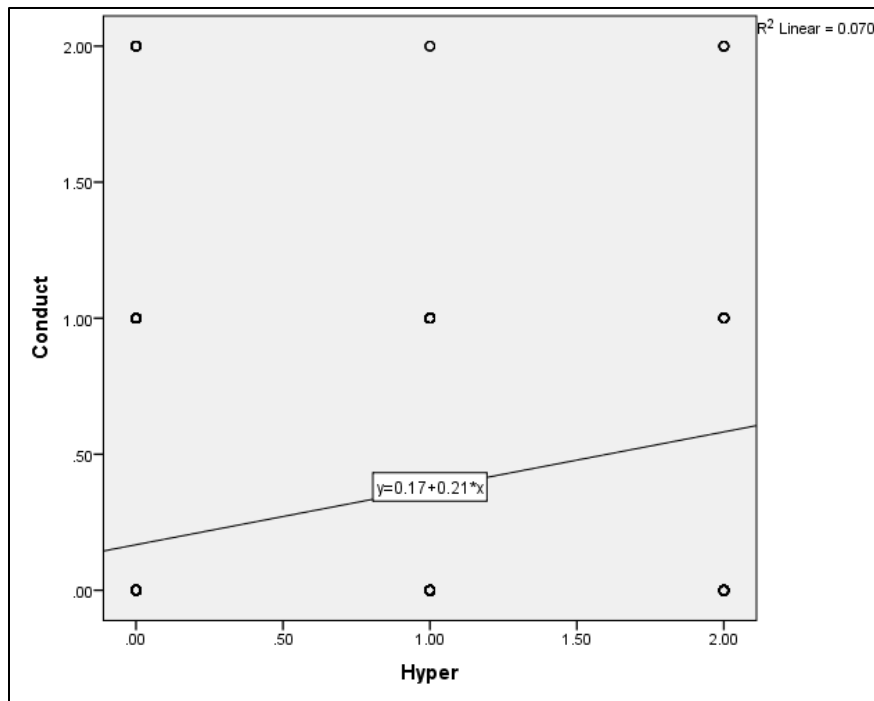


Figure 4.7 Hyperactivity and Conduct Linear Relationship for Hypothesis Three

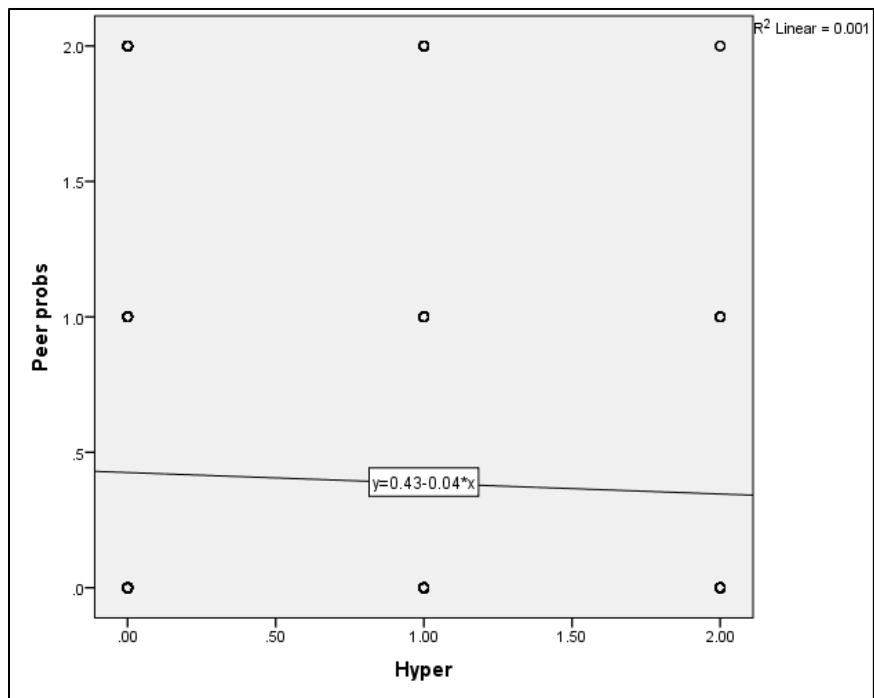


Figure 4.8 Hyperactivity and Peer Problems Linear Relationship for Hypothesis Three

Table 4.6 Box's Test of Equality of Covariance Matrices for Hypothesis Three^a

Box's M	57.828
F	9.517
df1	6
df2	126597.692
Sig.	.000
Tests the null hypothesis that the observed covariance matrices of the dependent variables are equal across groups.	
a. Design: Intercept + NORM_SPBD_STATUS	

Table 4.7 Levene's Test of Equality of Variances for Hypothesis Three^a

	F	df1	df2	Sig.
Hyper	18.087	1	1076	.000
Conduct	29.472	1	1076	.000
Peer probs	46.503	1	1076	.000
Tests the null hypothesis that the error variance of the dependent variable is equal across groups.				
a. Design: Intercept + NORM_SPBD_STATUS				

examining the results of the analysis. The level of measurement for each of them is a continuous interval scale. The SDQ norm prosocial score spreadsheet was built out from the norm summary data (Youthmind, n.d.b.) in Microsoft Excel and then imported into SPSS. Note that SPBD sampling was not completely random. The observations are assumed to be independent of one another, given the nature of the SPBD survey as well as SDQ norm data gathering techniques. Normal distribution can be violated as every group is larger than 30 (Pallant, 2007). Levene's test for equality of variances was found to be significant for hypothesis five, thus that *t*-test is considered with equal variances not assumed.

Analytical Results

Hypothesis One – Emotion Comparison. The difference in means between the NHIS 2016 norm group and the SPBD group is viewable in table 4.8. Table 4.9 is the result of an independent-samples *t*-test to compare the differences in scores between the entire NHIS 2016 norm group and the entire SPBD sample. As can be seen in table 4.9, there was no significant difference in scores for the norm group ($M = 0.1340$, $SD = 0.31942$) and the SPBD group ($M = 0.1419$, $SD = 0.29184$); $t(2120) = -0.292$, $p = 0.770$ (two-tailed). Moreover, the size of the difference in means (mean difference -0.00790 , 99% CI: -0.07768 to 0.06188) was calculated as eta squared = 0.00004 (calculated based on formula provided in Pallant, 2007, p.236). Thus the null hypothesis was not rejected, meaning there was not a statistically significant difference between the norm group and the SPBD group for emotional problems.

Table 4.8 Group Statistics for Hypothesis One

	NORM VS. SPBD	N	Mean	Std. Deviation	Std. Error Mean
Mean of CMHMF_2 and CMHMF_3 (RSCL2_E2 and RSCL3_E3)	NORM	1974	.1340	.31942	.00719
	SPBD	148	.1419	.29184	.02399

Hypothesis Two – Male Hyperactivity, Conduct, and Peer Problems Comparison.

Table 4.10 indicates the number of subjects considered, 1,044, and table 4.11 indicates the differences in means for males in the NHIS 2016 norm group and the SPBD group. There was a statistically significant difference when the means were considered as a profile, $F(3, 1040) = 58.20$, $p < 0.001$; Wilks' Lambda = 0.86 , partial eta squared = 0.14 , see table 4.12, thus the null hypothesis was rejected. The difference in means for

Table 4.9 Independent Samples Test for Hypothesis One

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. 2- tailed	Mean Diff- erence	Std. Error Diff- erence	99% Confidence Interval of the Difference	
									Low- er	Upper
Mean of CMHMF_2 and CMHMF_3 (RSCL2_E2 and RSCL3_E3)	Equal vari- ances ass- umed	.035	.851	-.292	212 0	.770	-.007 90	.02707	-.07 768	.06188

hyperactivity was not found to be statistically significant, $p > 0.01$, see table 4.13. The difference in means for conduct was statistically significant, $p < 0.01$, see table 4.13. The effect size was 0.07, indicating that 7% of the variance in conduct score is explained by SPBD status. The difference in means for peer problems was statistically significant, $p < 0.01$, see table 4.13. The effect size was 0.086, indicating that 8.6% of the variance in peer problems score is explained by SPBD status. Lastly, note that males in the SPBD group scored higher on conduct and peer problems than their norm counterparts, see table 4.11. This means that the male SPBD group had greater levels of reported conduct problems and peer problems than did the norm group.

Table 4.10 Between-Subjects Factors for Hypothesis Two

		Value Label	N
Norm vs. SPBD status	1	Male NORM	984
	2	Male SPBD	60

Table 4.11 Means and Standard Deviations for Hypothesis Two

	Norm vs. SPBD status	Mean	Std. Deviation	N
Hyper	Male NORM	.4360	.62172	984
	Male SPBD	.2833	.45442	60
	Total	.4272	.61420	1044
Conduct	Male NORM	.2470	.45666	984
	Male SPBD	.7833	.45442	60
	Total	.2778	.47310	1044
Peer probs	Male NORM	.34	.601	984
	Male SPBD	1.12	.415	60
	Total	.38	.619	1044

Table 4.12 Multivariate Tests for Hypothesis Two

Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
NORM_SP BD_STAT US	Pillai's Trace	.144	58.204 ^b	3.000	1040.000	.000	.144
	Wilks' Lambda	.856	58.204 ^b	3.000	1040.000	.000	.144
	Hotelling's Trace	.168	58.204 ^b	3.000	1040.000	.000	.144
	Roy's Largest Root	.168	58.204 ^b	3.000	1040.000	.000	.144
b. Exact statistic							

Table 4.13 Tests of Between-Subjects Effects for Hypothesis Two

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
NORM_SP BD_STAT US	Hyper	1.318	1	1.318	3.501	.062	.003
	Conduct	16.270	1	16.270	78.065	.000	.070
	Peer probs	34.521	1	34.521	98.412	.000	.086

Hypothesis Three – Female Hyperactivity, Conduct, and Peer Problems. Table 4.14

indicates the number of subjects considered, 1,078, and table 4.15 indicates the differences in means for females in the NHIS 2016 norm group and the SPBD group.

There was a statistically significant difference when the means were considered as a profile, $F(3, 1074) = 67.99$, $p < 0.001$; Wilks' Lambda = 0.84, partial eta squared = 0.16, see table 4.16, thus the null hypothesis was rejected. The difference in means for hyperactivity was not found to be statistically significant, $p > 0.01$, see table 4.17. The difference in means for conduct was statistically significant, $p < 0.01$, see table 4.17. The effect size was 0.081, indicating that 8.1% of the variance in conduct score is explained by SPBD status. The difference in means for peer problems was statistically significant, $p < 0.01$, see table 4.17. The effect size was 0.083, indicating that 8.3% of the variance in the peer problems score is explained by SPBD status. Lastly, note that females in the SPBD group scored higher on conduct and peer problems than their norm counterparts, see table 4.15. This means that the female SPBD group had greater levels of reported conduct problems and peer problems than did the norm group.

Table 4.14 Between-Subjects Factors for Hypothesis Three

		Value Label	N
NORM VS. SPBD status	1.00	Female NORM	990
	2.00	Female SPBD	88

Hypothesis Four – Male Prosocial Comparison. The difference in means between the SDQ norm group and the SPBD group is viewable in table 4.18. Table 4.19 is the result of an independent-samples t-test to compare the differences in scores between the male SDQ norm group and the male SPBD sample. As can be seen in figure 24, there was a significant difference in scores for the norm group ($M = 8.21$, $SD = 1.98$) and the SPBD group ($M = 4.63$, $SD = 2.03$); $t(1516) = 13.72$, $p < 0.001$ (two-tailed). The size of the difference in means (mean difference 3.58, 99% CI: 2.91 to 4.25) was computed as eta squared = 0.110 (calculated based on formula provided in Pallant, 2007, p.236),

Table 4.15 Descriptive Statistics for Hypothesis Three

	NORM VS. SPBD status	Mean	Std. Deviation	N
Hyper	Female NORM	.3980	.62246	990
	Female SPBD	.2614	.46718	88
	Total	.3868	.61223	1078
Conduct	Female NORM	.2071	.44580	990
	Female SPBD	.7045	.59033	88
	Total	.2477	.47877	1078
Peer probs	Female NORM	.35	.632	990
	Female SPBD	1.03	.466	88
	Total	.41	.647	1078

Table 4.16 Multivariate Tests for Hypothesis Three

Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
NORM_SP BD_STAT US	Pillai's Trace	.160	67.990 ^b	3.000	1074.000	.000	.160
	Wilks' Lambda	.840	67.990 ^b	3.000	1074.000	.000	.160
	Hotelling's Trace	.190	67.990 ^b	3.000	1074.000	.000	.160
	Roy's Largest Root	.190	67.990 ^b	3.000	1074.000	.000	.160
b. Exact statistic							

Table 4.17 Tests of Between-Subjects Effects for Hypothesis Three

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
NORM_SP BD_STAT US	Hyper	1.508	1	1.508	4.035	.045	.004
	Conduct	20.001	1	20.001	94.859	.000	.081
	Peer probs	37.320	1	37.320	97.123	.000	.083

indicating that 11% of the variance is explained by SPBD identity. Thus the null hypothesis was rejected. Notice that the male SPBD group scored lower, meaning that the

male SPBD group had lower reported prosocial functioning than did the male norm group.

Table 4.18 Group Statistics for Hypothesis Four

	Norm vs. SPBD status	N	Mean	Std. Deviation	Std. Error Mean
Prosocial score	Male NORM	1458	8.2140	1.97917	.05183
	Male SPBD	60	4.6333	2.03334	.26250

Table 4.19 Independent Samples Test for Hypothesis Four

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. 2-tailed	Mean Difference	Std. Error Difference	99% Confidence Interval of the Difference	
									Low-er	Upper
Prosocial score	Equal variances assumed	.146	.702	13.719	1516	.000	3.58066	.26100	2.90753	4.25379

Hypothesis Five – Female Prosocial Comparison. The difference in means between the SDQ norm group and the SPBD group is viewable in table 4.20. Table 4.21 is the result of an independent-samples t-test to compare the differences in scores between the female SDQ norm group and the female SPBD sample. Equal variances were not assumed for this equation (see hypothesis five sub section in assumptions for statistical analyses section, above). As can be seen in figure 26, there was a significant difference in scores for the norm group ($M = 8.61$, $SD = 1.73$) and the SPBD group ($M = 6.84$, $SD = 1.37$); t

(106.426) = 11.544, $p < 0.001$ (two-tailed). The size of the difference in means (mean difference 1.78, 99% CI: 1.37 to 2.18) was computed as eta squared = 0.087 (calculated based on formula provided in Pallant, 2007, p.236), indicating that 8.7% of the variance is explained by SPBD identity. Thus the null hypothesis was rejected. Notice that the female SPBD group scored lower, meaning that the female SPBD group had lower reported prosocial functioning than did the female norm group.

Table 4.20 Group Statistics for Hypothesis Five

	Norm vs. SPBD status	N	Mean	Std. Deviation	Std. Error Mean
Prosocial score	Female NORM	1321	8.6170	1.73428	.04772
	Female SPBD	88	6.8409	1.37202	.14626

Table 4.21 Independent Samples Test for Hypothesis Five

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. 2-tailed	Mean Difference	Std. Error Difference	99% Confidence Interval of the Difference	
									Lower	Upper
Prosocial score	Equal variances not assumed			11.544	106.426	.000	1.77605	.15384	1.37254	2.17955

Summary and Transition Statement

This chapter exhibited the data analysis for the study, including revised research questions and hypotheses, data screening procedures, and the results of each equation (t -

tests and MANOVAs). The SPBD group was found to have no statistically significant difference from the norm group in terms of emotional problems, and neither male nor female SPBD group were found to have a statistically significant difference from their norm counterparts in hyperactivity. The male SPBD group was found to have greater reported conduct problems and peer problems than the NHIS 2016 norm group. The male SPBD group was also found to have lower reported prosocial functioning than the SDQ norm group. The female SPBD group was found to have greater reported conduct problems and peer problems than the NHIS 2016 norm group. The female SPBD group was also found to have lower reported prosocial functioning than the SDQ norm group. Chapter five provides interpretations of the findings of this study, implications for social concerns, and recommendations for practitioners and researchers.

CHAPTER 5

DISCUSSION

This chapter is presented with the purpose of providing a synopsis of the study and to discuss the results. The chapter begins with an overview of the study and a summary of the results. The core aspects of the chapter involve interpretation of the findings in light of the literature and theory, implications for social change, and recommendations for action. The chapter closes with recommendations for further study followed by the conclusion.

Overview

Purpose of the Study

Children aged 4-7 years who are typically developing, yet who have a biological sibling with a diagnosable lifelong disability from the time of birth, represent a unique population. Over time, treatment has moved from the limits of an individual focus to more of a family focus, and the research documented in this dissertation reflects that change in focus. For the purpose of this study, typically developing siblings of persons with disabilities in general are referred to as siblings of persons with disabilities (SPDs) and typically developing siblings of persons born with lifelong disabilities are referred to as SPBDs. Where they are blended, they are referred to as SPDs. The siblings with actual disabilities are referred to as SDs. To clarify, this study excludes siblings of persons with

abnormalities resulting from maternal alcohol or drug use when such a cause is specified. The reason for this is that so much of sibling functioning is contingent upon systemic factors of the family (Minuchin & Fishman, 1981; Mandleco, Olsen, Dyches, & Marshall 2003; Whitaker & Bumberry, 2004).

When considering families of persons born with lifelong disabilities, it is possible support can be provided so that SPDs do not become “invisible children” (Naylor & Prescott, 2004, p. 199). Even when it comes to focusing on the SD, parents taking the time to clarify an understanding of the disability with SPDs can help diminish grudges they may be harboring toward the SD (Seligman & Darling, 2007). Therefore, when considering the families of persons born with lifelong disabilities, attending to aspects their typically developing siblings warrants some consideration.

Firstly, SPBDs have at least one sibling with a disability from the moment they meet him/her. Secondly, SPBDs (and all family members for that matter) may not be aware of the disability right away. While such naiveté can be difficult for the shock that may arrive with a diagnosis, it can also serve as a buffer against that shock in the early moments or days of getting to know the SD. Nonetheless, when a diagnosis does arrive, the diagnosis itself can be a relief because at least the presenting problem (i.e., What is going on with my brother or sister?) has a name, and classification helps with simplification and order in the mind of a siblings whose speculations about what is going on and what might happen later can vary far outside the realm of reality, such as thinking the disability is contagious (Siegel & Silverstein, 1994). Siegel and Silverstein also highlighted that children aged 5-11 believe in fairy tales, and SPDs engage in imagining their SD will one day no longer have the disability. McHugh (2003) indicated that SPDs

desire specific answers relevant to their age level, thus supporting the notion SPDs fare better when informed than they do remaining naïve long-term. While that much is known, little is known about the strengths and difficulties of SPBDs aged 4-7 years in the USA, as measured by a valid and reliable instrument.

Concern about persons with disabilities and courtesy stigma for family members has been a longstanding issue (Ali, Hassiotis, Strydom, & King, 2012; see also Gospel of John 9:1-2). The USA formerly had a policy of institutionalization of persons with certain developmental disabilities which lasted until JFK's administration intervened to move the nation toward more community-based care (Kennedy, 1963). The intervention helped pave the way for in-home care for persons with disabilities and necessarily involved their family members. The Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA, Pub. L. 97-248), was passed under the Reagan administration and resulted in providing for the healthcare costs of children with severe disabilities in the community rather than through institutionalization, regardless of family income (Catalyst Center, 2012).

SPDs may struggle with internalizing unspoken jealousy or resentment over their SD, as author Kate Strohm acknowledges self-discloses in her text *Being the Other One: Growing Up with a Brother or Sister who has Special Needs* (2005). At the same time, SPDs may be developing deep levels of empathy and sensitivity to the needs of others (Mulroy, Robertson, Aiberti, Leonard, & Bower, 2007), likely due to the many opportunities afforded them to practice such strengths. Thus, they may have deep strengths formed collaboratively with deep struggles. Conceptualizing this from a family systems perspective, it is worth noting that “resilience is forged through adversity, not despite it” (Goldenberg, Stanton, & Goldenberg, 2017, p.27).

The potential for a bimodal distribution of strengths and difficulties of SPDs also warrants consideration. For some SPDs, their struggles may overshadow their strengths. Indeed, Williams (1997) found through review of the literature for siblings of children with long-lasting health problems that 60% of publications showed heightened potential for problems, 30% did not identify potential for problems, and 10% found a mixture of both beneficial and problematic outcomes.

Theoretically, the family system is taken into account for overall SPBD strengths and difficulties, yet it is the SPBD in particular with which the current study warrants concern. When under stress, families tend to gravitate toward known modes of functioning (Minuchin & Fishman, 1981). For families dealing with a chronic stressor, without intervention it is conceivable that over time these modes of functioning will not only be practiced regularly but also solidified. For example, if an SPD takes on an early form of the placater role (Satir, 1972), it may be that the chronic stress in the family serves to support the roles of all family members and thus serves to reinforce the patterns the placater practices so that it becomes a lifelong role for the SPD.

Furthermore, while some studies on SPDs have been conducted outside of the USA such as the UK (e.g., Cunningham, 1996) and Australia (Giallo, Roberts, Emerson, Wood, & Gavidia-Payne, 2014), it remains to be seen whether findings from such studies would hold true in the USA with its varied demographics and multifaceted healthcare system which differs not only by socioeconomic status but also state by state. A major question is how SPBDs fare in terms of strengths and struggles when compared with norms for the same age-range. Do unique strengths indeed accompany unique difficulties, as measured by a valid and reliable instrument normed for children in the USA? At the

time of the study, there was no literature that answered this question specific to SPBDs through the use of an instrument such as the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997; Youthinmind, n.d.a.). Such was the aim of this study.

The purpose of the proposed study was to identify strengths and difficulties of persons 4-7 years of age who are siblings of persons born with lifelong disabilities (SPBDs) that are diagnosable from or prior to birth who are residing in the USA. This exploration was conducted through the administration of a survey containing the Strength and Difficulties Questionnaire (SDQ; Goodman, 1997; Youthinmind, n.d.a.) to parents who provided their perspective on their children who are SPBDs, and comparing those answers to results from the National Health Interview Survey for 2016 (CDC, 2017) and, due to the NHIS no longer inquiring about prosocial behavior, the summary data drawn from an earlier NHIS for SDQ norming (Youthinmind, n.d.b.). This study exists to shed light for counselors of this population so as to aid in the search for strengths at intake as well as potential areas for growth.

Implementation of the Study

The target population was SPBDs 4-7 years of age in the USA, more specifically reports from parents/guardians of SPBDs who are able to complete a questionnaire about the SPBDs. For the purpose of this study, parents/guardians of SPBDs were recruited within the state of South Carolina and nationally during the fall/winter of 2017-2018. See Appendix B for permission from Youthinmind to use an electronic version of the SDQ, and see Appendix C for paper versions representing both waves of electronic surveys. The sample for the USA norms in the same age-range was already determined by the NHIS 2016 data which was narrowed down to specifications for this study (related to

hypotheses one, two, and three) and the summary data for the norms (related to hypotheses four and five). That said, NHIS 2016 sample data used only the brief SDQ, which is drawn from the full SDQ. Thus, only certain questions were used rather than all 25. The purpose of using a more recent national sample for hypotheses one, two, and three, is so that the children in the comparison groups would be contextually closer (e.g., historically/chronologically) to the SPBDs where possible, and because the original norms are only available in the form of summary data so a MANOVA is not possible with that data.

Participants were recruited through email lists for agencies, website and private Facebook page postings (See Appendix D for a list) and a school, all of the above serving parents of children with disabilities. Typically developing siblings of persons with delayed diagnoses of such were still eligible so long as the condition was determined to have been present since birth. Siblings of persons with developmental disorders that were not diagnosable at birth (such as autism) were excluded from the study. With the systemic theory of human development in mind (discussed in chapter two), disorders directly attributable to maternal substance use (such as Fetal Alcohol Syndrome and Fetal Alcohol Effect) were excluded from the study as the nature of antecedent family functioning can have too great a bearing on SPBDs so as to confound the results, which is an ill-advised approach when the predictor variable is known and allows for selectivity. The target organizations for overall recruitment included local therapy clinics, Family Connection of South Carolina (an organization serving families of persons with special needs), a school for persons with special needs, and a blogger for caregivers of children with special needs.

The first wave of participants included recruitment through a private Facebook page and a blog for caregivers of persons with special needs. For those wishing to participate, the survey began with an informed consent page. There was also a section with forced field entry which required the primary diagnosis of the child born with a disability. The first wave of participants was recruited without gift a card offer in November, 2017, resulting in six usable responses. After limited responses, the second wave was recruited in January of 2018, with an expanded network of recruiters and a \$10 gift card offer through Tango Card which could be applied to multiple vendors. The first wave was considered anonymous, but the second wave considered confidential rather than anonymous, due to having to enter email address for gift card. IRB provided approval prior to each step taken in recruitment strategy. As an example of an agency from which participants were recruited in the second wave, The Therapy Place in Columbia, SC, was sent a sign to post along with a direct link (See Appendix E). This way, participants could scan the quick response (QR) code to be linked directly to the survey. The second wave of recruitment resulted in 142 usable responses. Thus, the total of the two waves resulted in 148 usable responses.

Sample size was primarily determined through Cohen's (1992) text *A Power Primer*. For determining sample size, it is efficient to choose the sample size based on the maximum amount need to suffice for one t-test based on medium effect size (e.g., 0.15) with $\alpha = 0.05$. The original minimum sample size intended was 64 for each group. In order to ensure robustness even with unequal sample sizes, Tabachnick and Fidell (2007; citing Mardia, 1971), indicate a sample size of 20 in the smallest cell is sufficiently robust. Pallant (2007) highlights that univariate normality can be checked using

descriptive statistics and multivariate normality can be checked through Mahalanobis distances. As the norm group from 2001 already had 2,779 (see below), females 1,321, and males 1,458, this left 64 participants to be recruited for the target group of females and 64 participants to be recruited for the target group of males (groups combined when needed for hypothesis one). As there was no way to determine the precise number of children in the sampling area that fit the target criteria before conducting the study, these sample sizes were considered tentative. However, in the end, 2016 NHIS data was able to be obtained for comparison, so it was used for hypotheses one, two, and three, whereas the earlier data used to norm the instrument is currently available in summary form only, so it was used for hypotheses four and five.

Instrumentation and Materials. The instrument for the proposed study was the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997; Youthinmind, n.d.a.), which is now available in over 40 languages (Youthinmind, n.d.a.). The SDQ is a one-page instrument with 25 questions that can be answered in three ways (not true, somewhat true, certainly true) and can be completed in about 5 minutes. With the SDQ, Goodman (1997) purports to measure 5 constructs: emotional problems, peer problems, conduct problems, hyperactivity, and prosocial behavior.

Data Analysis. If assumptions were met (i.e., about the independent variable not strongly influencing the covariate(s), equal regression slopes, and linearity) and likely covariates based on the literature, including theoretical framework were able to analyzed with the data, ANCOVAs and MANCOVAs would have been used with the following as covariates: income level and parent relationship status. In the end, there was inadequate data for using ANCOVAs or MANCOVAs. Thus, for the comparison of means for

emotional problems based on parent/guardian report of SPBDs 4-7 years of age, a t-test was used with an alpha level of 0.01 in place of a Bonferroni adjustment, given that the comparison is between the means of two groups. Note that since groups are being compared on a total five variables, a Bonferroni adjustment for an alpha level of 0.05 would lead to an alpha level of 0.01, so a principle of parsimony calls to simply use the strict alpha level of 0.01 for the t-tests. The same goes for males and females on prosocial behavior, separately. For comparing the profile of means for parent reports on three other subscales of the SDQ for SPBDs 4-7 years of age separated by gender with the corresponding profile of means for USA norms for each gender, MANOVAs were used. The three subscales are peer problems, conduct problems, and hyperactivity. Pending any significant difference found using the multivariate t-test, individual tests were run on each subscale to find which one or more showed significant difference. The predictor (independent) variable is the presence of a sibling born with a diagnosable lifelong disability, and the criterion (dependent) variable(s) is the mean separate subscales (where applicable) and the profile of means on the other three subscales of the SDQ, implying at least one mean for a subscale on the SDQ differs for the target group compared to the norm group. Earlier norm data was not available, except in summary form, because of software difficulties encountered through the NHIS website maintained by the CDC (see Appendix F). Furthermore, because the NHIS no longer tracks the prosocial behavior of children, the summary data from the SDQ website (Youthinmind, n.d.b.) based on the norm data is used for the analyses for hypotheses four and five.

The SDQ has been demonstrated to be a valid and reliable instrument for assessing multiple characteristics of children 4-7 years of age based on parental

perceptions. Furthermore, the SDQ can be conceptualized as assessing three constructs for low-risk children in the USA, but because mixed results have been shown for assessing risk-levels for mental health problems of SPBDs, the five factor model was used in this study. A t-test was performed to assess differences in parental perception of emotional problems between SPBDs and the norm group for the USA, with an alpha level of 0.01 in place of Bonferroni adjustment, and for the remaining three factors comparable with 2016 NHIS data (conduct problems, peer problems, hyperactivity-inattention) a MANOVA was conducted comparing males to males for each group, and a separate MANOVA was conducted comparing females to females for each group. Lastly, t-tests were performed to assess differences in parental perception of prosocial behavior between male SPBDs and their norm counterparts for the USA based on summary data from the SDQ website (Youthinmind, n.d.b.), and the same was done with females, with alpha level of 0.01 in place of a Bonferroni adjustment in both cases.

Review of the questions. The revised research questions and hypotheses (due to the limitations of the data that could be accessed at the time of the study) are stated below.

Revised Research Questions:

1. Is there a difference between parental perceptions of SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared on emotional problems, as measured by the SDQ?
2. Is there a difference between parental perceptions of male SPBDs 4-7 years of age and the norms for male children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ?

3. Is there a difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ?
4. Is there a difference between parental perceptions of male SPBDs 4-7 years of age and the norms for male children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ?
5. Is there a difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ?

Revised Alternative Hypotheses:

1. There is a significant difference between parental perceptions of SPBDs 4-7 years of age and the norms for children of the same age-range in the USA, when they are compared on emotional problems, as measured by the SDQ.
2. There is a significant difference between parental perceptions of male SPBDs 4-7 years of age and the norms for male children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ.
3. There is a significant difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared simultaneously on conduct problems, hyperactivity, and peer problems, as measured by the SDQ.

4. There is a significant difference between parental perceptions of male SPBDs 4-7 years of age and the norms for children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ.

5. There is a significant difference between parental perceptions of female SPBDs 4-7 years of age and the norms for female children of the same age-range in the USA when they are compared on prosocial behavior, as measured by the SDQ.

Definitions of constructs based on SDQ criteria.

Conduct problems are construed as externalizing behavior, e.g., a history of frequent tantrums, lack of compliance with authority, conflict with peers, deceit, and theft.

Emotional problems are construed as internalizing behavior, e.g., frequently verbalizing concern over physical maladies, a host of fears and worries, frequently low mood, and worrisome feelings or behaviors in novel settings,

Hyperactivity is construed as excessive psychomotor behavior along with some externalizing behavior, e.g., extremely high level of activity or lack of ability to settle down, consistent fidgeting, lack of sustained focus, lack of forethought, lack of assignment completion.

Peer problems are construed as lack of mutuality with other children and may be considered relational manifestations of internalizing behavior, e.g., habitually isolating self in play, lack of any close companion, disliked by peers, harassed by peers, and being better at relating with adults than with peers.

Prosocial behavior is construed as initiative toward amiable relations with others, e.g., conscientious of others' affective states, caring, generous, nice to those of lesser age, and stepping up to be of service to others.

Brief summary of the findings. The SPBD group was found to have no statistically significant difference from the norm group in terms of emotional problems, and neither male nor female SPBD group were found to have a statistically significant difference from their norm counterparts in hyperactivity. The male SPBD group was found to have greater reported conduct problems and peer problems than the NHIS 2016 norm group. The male SPBD group was also found to have lower reported prosocial functioning than the SDQ norm group. The female SPBD group was found to have greater reported conduct problems and peer problems than the NHIS 2016 norm group. The female SPBD group was also found to have lower reported prosocial functioning than the SDQ norm group.

Interpretation of Findings

Regarding emotional problems, results showed differences were not significant between SPBDs and their norm counterparts. In light of that, parental concerns about the emotional (i.e., internalizing) impact of having an SD during the ages of 4-7 may be alleviated. Nonetheless, this should not be taken to imply that SPBDs at a later age range will not have significant differences in internalizing symptoms compared to their norm counterparts. Recall the finding from Williams (1997) that findings are mixed about outcomes related to SPDs overall, of which this target group is a subset sample.

Regarding hyperactivity, again results showed differences were not significant between SPBDs, male or female, and their norm counterparts. Again, this is not surprising in light of the literature review for this study, as there was no indication of the majority SPDs being higher than the norm on hyperactivity, though Giallo, Gavidia-Payne, Minett, and Kapoor (2012) did find 20-30% of their sample of 10-18-year-old

SPDs in Australia had results revealing an at-risk or clinical range score for overall difficulties, hyperactivity-inattention problems, conduct problems, and peer problems. Take note also that Emerson and Giallo (2014) found that SPDs in Australia actually had lower measures for conduct difficulties, emotional difficulties, hyperactivity, and prosocial behavior, but that effect sizes were minor, and they also did not find any decompensation among the target group of siblings over a period from four to five years of age and six to seven years of age.

Male SPBDs were found to have significant differences than their norm counterparts on conduct problems and peer problems ($p < 0.01$, effect sizes 0.081 and 0.083, respectively), both of those in a maladaptive direction. Furthermore, they were found to have significantly different scores on prosocial functioning as well ($p < 0.01$, effect size 0.110). Furthermore, female SPBDs were found to have significant differences than their norm counterparts on conduct problems and peer problems ($p < 0.01$, effect sizes 0.07 and 0.086, respectively), both of those in a maladaptive direction. Furthermore, they were found to have significantly different scores on prosocial functioning as well ($p < 0.01$, effect size 0.087). Note that there was not any extreme effect size in this study, which indicates that other factors besides being an SPBD may be at play in leading to the scores. Nonetheless, the effect sizes represented are not to be ignored.

In keeping with a systemic mindset, this may be due to an average SPBD in this age range being somewhat of an externalizing a symptom-bearer for the family. The findings of this study are may be considering in light of the findings of Giallo, Gavidia-Payne, Minett, and Kapoor (2012), which involved use of the SDQ with Australian youth 10 – 18 years of age and found that they did report greater emotional problems and

behavioral problems than a norm sample. Furthermore, the findings are consistent with the findings of Goudie, Havercamp, Jamieson, and Sahr (2013), in which they tested parental perception of behavioral and emotional problems for SPDs. When compared with typically developing siblings, they found that SPDs were reported to have more problematic relationships, more problematic psychological, school, and leisure functioning. At the second period of measurement for the study, they found that for SPDs considered significantly impaired when it comes to functioning the percentage had increased from 16.0% to 24.2%. Goudie et al. concluded that the focus in healthcare is often on the SD, yet they called upon professionals to think about approaches that take into account all members of the family.

Additionally, given that the majority of children represented in the current study are Hispanic, consider that Long et al. (2013) examined expression of emotions and emotion communication between siblings and parents of children with intellectual disabilities, comparing a Latino sample with a non-Latino white sample; all target children 8 – 15 years of age. The study warrants consideration through a systemic lens. They highlighted the literature's lack of focus on the cultural backgrounds of SPDs, and cited multiple problems that could ensue due to this oversight, including that what may be considered helpful by one group could be deemed maladaptive by another group. Long et al. found that SPDs reported somewhat greater difficulty with emotion expression than their matched counterparts. They indicated that, when it comes to cultural differences in emotion expression and communication, those differences can lead to a heightened potential for problems with emotional adjustment among SPDs who are Latino. It may be that emotional difficulties for children four to seven years of age in the current study are

expressed through externalizing symptoms. An alternative lens to consider has to do with sibling relationships, and that is discussed in the implications section.

Note that the findings for the current study are inconsistent with Mandleco and Webb's (2015) literature review which indicated SPDs (including SPBDs of SDs with Down syndrome), compared to siblings of typically developing children, were said to have "better self-concepts" (p. 151), exhibited more caring, kindness, and helpfulness, and took on increased responsibilities in the home. However, Mandleco and Webb's study is limited in a compounding manner based on the limitations of each article in their literature review. Moreover, Graff et al. (2012) indicated that SPBDs acknowledge both difficulties and beneficial aspects of their experience, and that may be important to take into when dealing with SPBDs over time, as the current study represents a mere snapshot. Again, in considering mixed results of the literature, take into account that Emerson and Giallo (2014) found that SPDs in Australia actually had lower measures for conduct difficulties, emotional difficulties, hyperactivity, and prosocial behavior, but that effect sizes were minor, and they also did not find any decompensation among the target group of siblings over a period from four to five years of age and six to seven years of age.

Tying all of the above together into a workable model for explanation, the possibility exists that SPBDs grow along a different pathway than their typically developing counter. Rather than a series of standard interlocking S-curves of growth (comparable to the Sigmoid), it may be that SPBDs experience deeper troughs when in transition, yet also experiencing greater stability and determination along the way. For example, see figure 5.1 for a semblance of an oft-cited metaphor for development in the

business world, and which also may apply to human growth and development typical human development, namely the metaphor of the sigmoid curve (Handy, 1994).

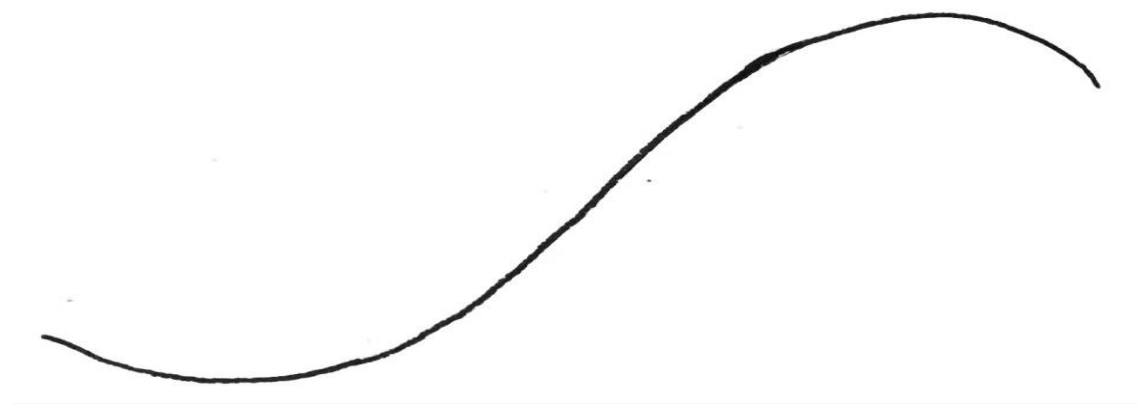


Figure 5.1 Sigmoid Curve (adapted from Handy, 1994)

Handy (1994) writes:

We start slowly, experimentally, and falteringly; we wax and then we wane... It is the story of the British Empire... It is the story of a product's life cycle and of many a corporation's rise and fall. It even describes the course of love and relationships. If that were all, it would be a depressing image... The secret to constant growth is to start a new sigmoid curve before the first one peters out (pp. 50-51).

Handy (1994) goes on to share how starting a new curve would actually play out, albeit more in an organization context. He observes that people can wait too long to change curves. He also indicates that in between curves there is a tumultuous period, and illustrates it through shading overlapping areas in the curves, see figure 5.2 for a

semblance. Thus, one can reason that human development, in a rudimentary way, may appear like figure 5.2, with the dotted lines representing perpetual decline if factors in one's life do not lead to a course correction (note that a course correction would lead to a short-term decline yet a long-term gain):

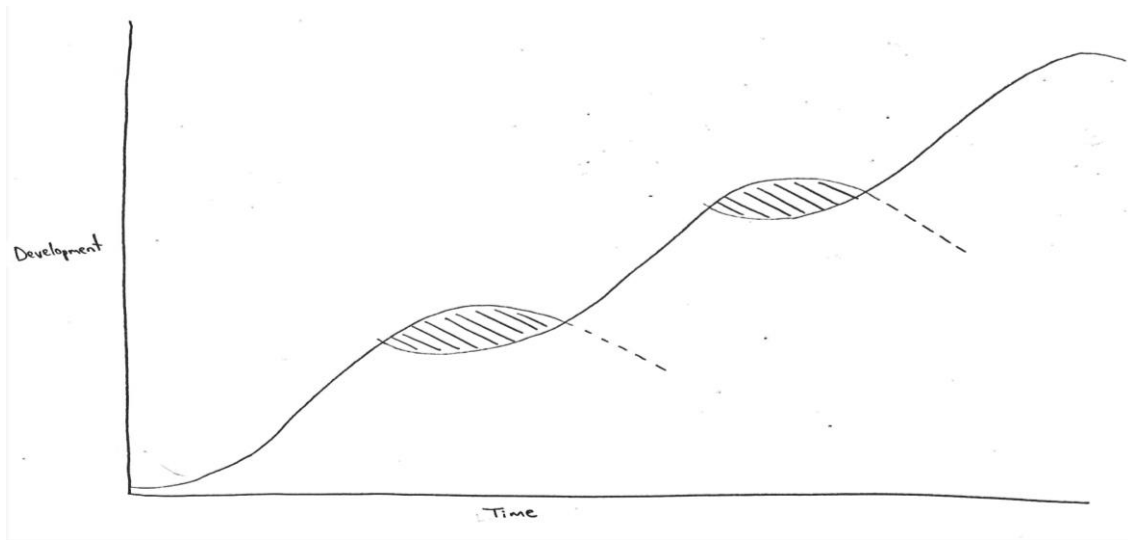


Figure 5.2 Overlapping Sigmoid Curves (adapted from Handy, 1994)

Systemically speaking, Minuchin wrote of this phenomenon within a family in his observation that the family is a living organism of attached individuals; a system that is ever-adjusting to the new information which it encounters (Minuchin & Fishman, 1981). Minuchin shared that because the system is coming into contact with new information, it will be simultaneously propelled toward change while being compelled toward homeostasis. That dynamic can be considered part of the shaded area in the illustration above.

Next, consider that the sample of SPBDs may be undergoing development more like figure 5.3, and that some transitions for a sample that is nearly 2/3 Hispanic in the 4-7-year-old age range in the USA at this time in history may lead to deeper troughs

between curves for them than for their norm counterparts (considering, for example, one major change that typically occurs for nearly children in the USA is the transition from home to compulsory schooling).

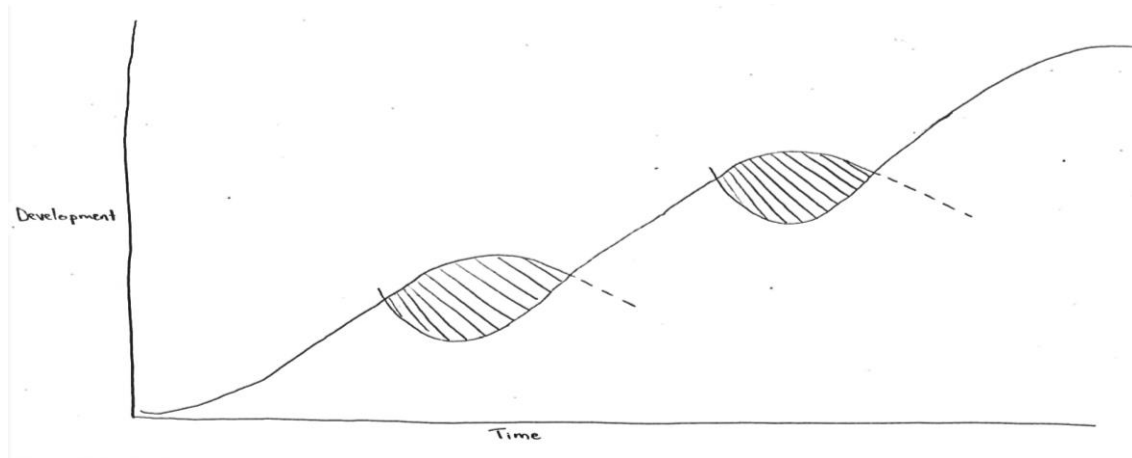


Figure 5.3 Overlapping Sigmoid Curves with Deepened Troughs

Social Change Implications & Recommendations for Action

Knowledge Generation

This study serves to generate heretofore veiled knowledge in the area of strengths and difficulties for SBPDs. Thus, practitioners can begin exploring the findings with clients who resemble the sample, and researchers can look to this study as a model for future studies. Furthermore, a view to long-term strengths can lead to social change in that potentially deficit-laden perspectives of SPBDs can be replaced with a view that includes their strengths as co-existing with any difficulties. Moreover, if this study is replicated then a counselor may be able to hypothesize the presence of certain manifestations of strength and difficulty for clients who are SBPDs, as well as use this model for future research.

Professional Application

Decades ago, it was known that SPDs may be more likely to present for counseling than the child with a disability (Poznanski, 1969). While not a complete affirmation of that assertion, the findings on externalizing symptoms in the current study do appear to support the notion that SPBDs have greater reported struggles than the norm. This is part of the reason why it is essential to search for strengths at an intake, because it is from strengths that clients grow (Ivey & Ivey, 2007), and often from growth that presenting problems are overcome or at least become manageable. Therefore, if counselors explore clients' strengths at intake, for example through use of the SDQ (Goodman, 1997; Youthinmind, n.d.a.), this tactic exhibits a focus on growth rather than mere symptom reduction, aids in the building of the therapeutic alliance, and provides a springboard for delving further into idiomatic strengths of the client/family (Duncan, 2014).

As the therapeutic alliance is said to have a greater effect on outcomes than theoretical approach (Duncan, 2014), an emphasis on building up the alliance should fit with a number of therapeutic models and thus serve to inform the field of counseling at large. As Duncan points out, counselors skilled at building the therapeutic alliance focus on it right from the start.

While child therapists may nod to the finding that behavioral therapy for children outperforms other theoretical approaches (Weiss & Weisz, 1995), they may also acknowledge this finding is based on statistical significance, not clinical significance. Family systems approaches have also been shown to be efficacious in families dealing with a variety of presenting problems (e.g., see Goldenberg, Stanton, and Goldenberg,

2017, ch. 16). Play therapists come to that modality from a variety of backgrounds and yet are for the most part agreed on helping children through means of play, toys, art, and metaphors. So, regardless of the theoretical approach, the counselor during the intake with a child SPBD might manifest a bit of an “Aha” realization in counseling when lighting upon the discovery the client/identified patient is an SPBD. The counselor could say “Well I’m willing to bet that you have some real strong parts of you and that you have a certain way of seeing others and the world that could help us work together for you to overcome [insert presenting problem]. I’m also willing to bet that the same things that help make you strong also led to some struggles you may or may not think about much, and we can look at those too. Either way, you and your family can help me know what your world is like, and what their world is like, and we can go from there.”

Counselors equipped with the knowledge gleaned from this study can also have some ready-made points to discuss with families of SPBDs in order to normalize some of their struggles and promote their strengths. Moreover, classification helps with simplification and order in the mind of a siblings whose speculations about what is going on and what might happen later can vary far outside the realm of reality, such as thinking the disability is contagious (Siegel & Silverstein, 1994). Siegel and Silverstein also highlighted that children aged 5-11 believe in fairy tales, and SPDs engage in imagining their SD will one day no longer have the disability. McHugh (2003) indicated that SPDs desire specific answers relevant to their age level, thus supporting the notion SPDs fare better when informed than they do remaining naïve long-term. Thus, all counselors may be helpful in facilitating parental education of SPBDs about the SDs’ abilities and disabilities.

Family counselors involved with families of children born with disabilities would do well to heed Minuchin and Fishman's counsel that "Above all, the spouse holon must learn to deal with conflict" (1981, p.23), here using the term holon represent a practically inseparable unit. If parents do not know how to manage conflict, their children will not have this modeled for them and thus lack skills for functioning in nearly any setting. Family counselors who assess and find that parents would be helped by a couple's therapy should frontload that, possibly through discussion of the identified patient being a symptom bearer hailing the need for the parents to work on their relationship. Note that Daire, Munyon, Carlson, Kimemia, and Mitcham (2011) found no significant differences in distress of parents of children with and without special needs. Thus, parents of children with disabilities who are struggling with conflict may be helped through established relationship education programs such as the Prevention and Relationship Education Program, also known as PREP (Markman, Stanley, & Blumberg, 2010).

After or concurrent with addressing any need for dyadic intervention with the parents, family counselors may find it particularly useful to address the domains for quality of life of SPDs discussed by Moyson and Roeyers (2012) as a means of processing concerns with SPBDs and their families. Those domains are as follows:

1. Joint activities
2. Mutual understanding
3. Private time
4. Acceptance
5. Forbearance
6. Trust in well-being

7. Exchanging experiences among SPBs
8. Social support
9. Dealing with the outside world (Moyson & Roeyers, 2012, p. 93)

SPBs may be helped by generating a personalized list of domains for quality of life.

Family counselors who incorporate play therapy can help SPBs exhibit their perception of the family through the creation of a play genogram (see McGoldrick, Gerson, Petry, & Gill, 2008). In this context, the SPB can describe the reason for choosing particular objects to represent family members. According to McGoldrick et al., allowing for metaphor also brings with it the opportunity to consider change.

After constructing a play genogram, family therapists, SPBs, and other family members may choose certain objects to maintain meaning over more than one session. For identified patients with particular concerns already named, counselors can tell story stems and ask SPBs and family members to collaboratively complete the stories in a chainlike fashion, or ask each person to come up with an ending and then process how perspective influences the outcome. Family therapists may also model for parents how to facilitate sibling play interaction with a hands-off approach to letting children resolve conflicts while parents are simply present rather than immediately intervening.

Clinical mental health counselors meeting with SPBs and any other family members in the 4-7-year-old age range may wish to use at least some level of play in their counseling approach, and thus may wish to incorporate some of the strategies outlined above for family therapists. During any individual time with SPBs, the counselor may take out translucent pages with different colors and ask SPBs what

feeling each color may represent. Afterward, the counselor and SPBD can practice holding up the sheets in front of their faces and displaying the expression that best matches the feeling represented by the color. Then, they can see how long they can maintain the expression without laughing or getting tired of it, how quickly they can change sheets, and even how they can combine them. Afterward, they can ask if the SPBD ever sees anyone through a particular sheet, and how it may be helpful to talk about it or even change colors to see if it helps.

School counselors can use the information found through this study and the review of the literature to inform interventions and request permission from parents to introduce SPBDs to one another, particularly if the SDs share similar diagnoses. Note that SPDs in the Moyson and Roeyers (2012) study indicated the importance of sharing their experiences with other SPDs, and school counselors would be the most poised counselors to network with area schools and advocacy agencies in the region about recruitment strategies specific to SPBDs who attend area schools. For example, school counselors could recruit SPBDs for *Sibshops* (Meyer, Vadasy, & Fewell, 1985; Sibling Support Project, 2015), workshops designed to facilitate connection and support for siblings of persons with disabilities.

Furthermore, school counselors would be aware of the multiple contexts with which Hispanic children interact, including possibly speaking one language at home and another at school. Long et al. (2013) found that when it comes to cultural differences in emotion expression and communication, those differences can lead to a heightened potential for problems with emotional adjustment among SPDs who are Latino. School counselors may use that information along with the findings from the current study to

communicate with parents, administrators, and students to formulate plans to help those who are struggling. The point in identifying struggles is to guide treatment as well, thus school counselors can work toward that end by providing not only a therapeutic setting where SPBDs can come to share their struggles, but also a place where they can commemorate their strengths, family strengths, and the strengths of the SD. For families who have difficulty navigating the social services system, school counselors can inform them of resources such as local or regional advocacy organizations, workshops and other events, and websites (e.g., <https://www.siblingsupport.org/>, <https://childmind.org>), as well as potential available services, especially respite care as indicated by Welch et al. (2012).

Social Change

As this research is promoted through presentation and publication, the wider world will be made aware of the difficulties faced by SPBDs. Further study can delve into the particular strengths of this sample item by item rather than merely the overall prosocial score. Thus, parents may find the results useful in considering whether or not to have another child if they already have a child born with a disability. Teachers may find the information useful with regard to engaging SPBDs as well as their families. Furthermore, policymakers, charity organizations, and non-profits will be better equipped to render funding decisions about support programs such as *Sibshops* (Meyer, Vadasy, & Fewell, 1985; Sibling Support Project, 2015), workshops designed to facilitate connection and support for siblings of persons with disabilities.

Limitations

Threats to validity for this study include a lack of randomization (because the study is non-experimental), subject selection (through recruitment strategies involving local agencies), other-report (parent report about the child), and participant bias in answering the SDQ. As there is no manipulation of variables involved, the furthest the conclusions can be drawn is to indicate that there seems to be evidence of particular findings, yet this points to a potential cause, not clear proof (Lodico, Spaulding, & Voegtler 2006).

A further limitation is that this study involves a use of SDQ subscale scores for parent perspectives of SBPDs 4-7 years of age who are residing in the USA, in comparison the national norms on those subscales. Thus, it is limited to the operational definitions supported by the instrument. Furthermore, the greatest effect size indicated that 11% of the difference in means of male prosocial scores was attributable to SPBD status, and the rest of the effect sizes indicated less than 10% of the difference was due to SPBD status.

The researcher chose to recruit participants heavily within South Carolina as this is the state in which the researcher has a network of individuals and organizations that may be called upon to participate or recruit participants. The researcher sought participants through word of mouth and through organizations which serve families of persons born with disabilities and through online platforms which serve these families.

Recommendations for Further Study

Pending replication, the generalizability of the current study may be confirmed or disconfirmed. Future studies would be better served by comprehensive control group

rather than national norms, and consideration of covariates including but not necessarily limited to: (a) family composition; (b) household income; (c) relative success or difficulty in navigation of social service system, if any social services applicable; (d) level of aid to SD; (e) use of respite services; and (f) use of other services related to family aid. Future studies may include: (a) target studies related to specific disorders; (b) siblings older and younger; (c) different age groups; (d) qualitative research on adult sibling caregivers; (e) cross-sectional studies to inform theory regarding development; and (f) longitudinal studies to assess sigmoid curve growth or other patterns of development.

Conclusion

The current sample of male and female siblings of persons born with disabilities (SPBDs) differ from the norm for each sex in the USA when it comes to reported conduct problems, peer problems, and prosocial functioning. It may be that their functioning at this time of life is tested by a number of factors, not least of which is parental, familial, and extra-familial continual adjustment to the presence of a sibling born with a lifelong disability. As mentioned above, the trajectories for SPBD development may involve greater troughs as they progress through life, particularly during early childhood. What begins with deep struggle may culminate with enduring strength, for the two are forged “in the same crucible” (Wofford & Carlson, 2017, p. 403) and the former begets the latter when adequate support is supplied.

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APPENDIX A: IRB APPROVAL



OFFICE OF RESEARCH COMPLIANCE

INSTITUTIONAL REVIEW BOARD FOR HUMAN RESEARCH APPROVAL LETTER for EXEMPT REVIEW

Joseph Wofford
College of Education
Department of Educational Studies / Counselor Education
Wardlaw
Columbia, SC 29208

Re: Pro00071925

Dear Mr. Wofford:

This is to certify that the research study "*Strengths and Difficulties of Typically Developing Siblings of Persons Born with Lifelong Disabilities*" was reviewed in accordance with 45 CFR 46.101(b)(2), the study received an exemption from Human Research Subject Regulations on 10/26/2017. No further action or Institutional Review Board (IRB) oversight is required, as long as the study remains the same. However, the Principal Investigator must inform the Office of Research Compliance of any changes in procedures involving human subjects. Changes to the current research study could result in a reclassification of the study and further review by the IRB.

Because this study was determined to be exempt from further IRB oversight, consent document(s), if applicable, are not stamped with an expiration date.

All research related records are to be retained for at least three (3) years after termination of the study.

The Office of Research Compliance is an administrative office that supports the University of South Carolina Institutional Review Board (USC IRB). If you have questions, contact Arlene McWhorter at ardenem@sc.edu or (803) 777-7095.

Sincerely,

Lisa M. Johnson
ORC Assistant Director
and IRB Manager

APPENDIX B: APPROVAL FROM YOUTHINMIND TO USE SURVEY VERSION
OF SDQ

Youthinmind <youthinmind@gmail.com>

Sun 11/5/2017, 5:35 AM

WOFFORD, JOSEPH;

Youthinmind SDQScore <sdq.scoring@gmail.com>;

+3 more

Action Items

Hi Joseph,

We are now happy with your online version of the SDQ.

Thank you for your time and effort to make all corrections we asked for.

Please send me your full address and I will email you an invoice for one-off authorization charge.
When we receive your payment, we will issue a license to use the SDQ.

Best wishes,

Helena

Youthinmind <youthinmind@gmail.com>

|Wed 11/15/2017, 9:45 AM

Dear Rufus,

We have now received your payment and are pleased to authorize you to use the SDQ under the terms of the license (please see below – terms (c) and (e) having been part of your pre-authorization).

I hope all works out well and we will be glad to respond if you have further queries at any point.

Best wishes,

James Goodman
Youthinmind Limited

Licensees pay a small license fee to Youthinmind (currently 0.40 USD per SDQ administered). Please note that this is only for online systems – we do not currently license Apps.

The conditions of use of the SDQ include:

- a) Licensees need to keep track of the exact number of SDQs administered, and be able to justify, if requested, the total that they declare.
- b) Licensees pay Youthinmind the license fee at regular intervals: quarterly, 6-monthly or yearly at the Licensee's convenience. The fee is strictly per item, with no reduction for large users. (Since we expect users to save money by using the license, larger users are already advantaged by saving larger amounts of money).
- c) The web presentation of the SDQ cannot involve any change in wording and needs to be as close as possible to the standard paper version in appearance – no bright colours, flashing icons etc. This is because changes in presentation can undermine the comparability of SDQ data collected in different ways, making it harder to combine or contrast SDQ data from different studies or clinics. The copyright notice on the paper version also needs to be present on the electronic version. **To ensure that these terms are respected, we do need to see and approve of the licensee's proposed online version before you are authorized to use it.**
- d) The license will be revoked if the SDQ were being used in a way likely to bring it into disrepute.
- e) There is a one-off authorization charge of 200 USD at the time of authorization

Please let us know if you need further clarification.

APPENDIX C: FIRST AND SECOND WAVE SURVEYS

FIRST WAVE SURVEY

[***Minor Revisions*** Minor revisions due to request from representative for Strengths and Difficulties Questionnaire, also corrected order and language of some demographic questions.

This will all be in digital form on Survey Monkey. Here is an updated link so that you can view the survey directly: <https://www.surveymonkey.com/r/Testing2SibsSDQ>***]

You are being asked to participate in this study via online survey software because you are at least 18 years of age and you are the parent or legal guardian of a child born with a lifelong disability who may have a typically developing biological sibling (i.e., non-disabled) who is 4-7 years of age, both of whom were born in the USA and currently living in the same home with you in the USA. If this does not describe you, please do not continue and close out your browser. The demographic information should take about 5 minutes to complete and the questionnaire should take an additional 5-10 minutes to complete.

The purpose of this study is to identify both strengths and difficulties of children 4-7 years of age, without disabilities, who have a biological sibling born with a lifelong disability (example: born blind, born with a chromosomal abnormality, etc). Please note that siblings of children with disabilities from maternal substance abuse are excluded from this study. This study also excludes siblings of children whose only diagnosis is autism as it is not yet known whether autism can ever be diagnosed at birth. If a diagnosis was not detected at or prior to the time of birth, but could have been caught otherwise, the biological sibling may still be included in the study. This study seeks to shed light for counselors of this population so as to aid in the search for strengths at an intake session as well as potential areas for growth. The study uses the Strengths & Difficulties Questionnaire (USA version developed by Robert Goodman in 2005) to gather parent/guardian reports about the functioning of the sibling in five areas: prosocial skills (strengths), conduct problems, emotional problems, hyperactivity-inattention, and peer problems.

First, you will complete the demographic information form, followed by the Strengths and Difficulties Questionnaire. Participation in this study is voluntary and will be anonymous (other than your IP address) as you will not be asked to reveal your identity and data will be reported in an aggregate form. You do not have to answer any question you do not wish to answer, as you may discontinue participation at any time. No payment is provided for participating in this study. If you have the only child in the study / the USA who has a sibling with an extremely rare disorder, others may know you participated when reviewing the list of siblings' disabilities. The questionnaire you are being asked to complete is about the typically developing sibling (non-

disabled) who is 4-7 years of age.

Please direct any questions or directions to be excluded from the study to the principal investigator, Joseph Rufus Wofford, via email at wofforjr@email.sc.edu.

By entering information in the demographic form and/or the questionnaire, you are agreeing that you have read and agree to the information indicated above and to have your answers included in the study.

*Do you consent with your personal data being processed as described above? You must click Yes in order to take the survey.

- ☐ Yes
- ☐ No

Demographics form

Child with a lifelong disability diagnosable at or prior to birth:

Age of child with a lifelong disability diagnosable at or prior to birth:

Gender of child with a lifelong disability diagnosable at or prior to birth:

Race/ethnicity of child with a lifelong disability diagnosable at or prior to birth: (Please choose only one.)

Primary diagnosis of child with a lifelong disability diagnosable at or prior to birth:

Typically developing (non-disabled) biological sibling:

Age of typically developing (non-disabled) biological sibling:

Gender of typically developing (non-disabled) biological sibling:

Race/ethnicity of typically developing (non-disabled) biological sibling: (Please choose only one.)

Relationship of typically developing (non-disabled) biological sibling to the child with a lifelong disability:

Informant information

Your relationship to the child born with a lifelong disability:

Your relationship to the typically developing (non-disabled) biological sibling:

What is your age?

What is the highest level of education you have completed?

Which of the following categories best describes your employment status?

Which of the following best describes your current relationship status?

Household information

In what state or U.S. territory do you and the children live at this time?

Total number of children living in the home with you at this time:

Average monthly income for your household from any and all sources, in whole dollars:

Focus for the Strengths and Difficulties Questionnaire

The following page contains the Strengths and Difficulties Questionnaire. The focus for your answers must be only for the typically developing (non-disabled) biological sibling 4-7 years of age.

- ☐ I understand, and I will answer the questionnaire on the next page for the typically developing (non-disabled) biological sibling only.

[Survey software version is slightly different (please see link on first page of this document). Also, on the survey software, questions are blocked in groups of five.]

Strengths and Difficulties Questionnaire

P or T 4-10

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of the child's behavior over the last six months or this school year.

Child's name

Male/Female

Date of birth

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless, overactive, cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often complains of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shares readily with other children, for example toys, treats, pencils	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often loses temper	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather solitary, prefers to play alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally well behaved, usually does what adults request	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many worries or often seems worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has at least one good friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often fights with other children or bullies them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often unhappy, depressed or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally liked by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easily distracted, concentration wanders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous or clingy in new situations, easily loses confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often lies or cheats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Picked on or bullied by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often offers to help others (parents, teachers, other children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinks things out before acting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steals from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets along better with adults than with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many fears, easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Good attention span, sees work through to the end	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Signature

Date

Parent / Teacher / Other (Please specify):

Thank you very much for your help

© Robert Goodman, 2005

SECOND WAVE SURVEY

[***Minor Revisions*** Minor revisions due to adding an incentive, thus also adding question about email address. This will all be in digital form on Survey Monkey. Here is an updated link so that you can view the survey directly (you can enter an email address for the last question and will be sent a demo (i.e., fake) \$10.00 gift card as Tango Card has set this up for me to give you a demo): <https://www.surveymonkey.com/r/Testing2SibsSDQ>***]

You are being asked to participate in this study via online survey software because you are at least 18 years of age and you are the parent or legal guardian of a child born with a lifelong disability who may have a typically developing biological sibling (i.e., non-disabled) who is 4-7 years of age, both of whom were born in the USA and currently living in the same home with you in the USA. If this does not describe you, please do not continue and close out your browser. The demographic information should take about 5 minutes to complete and the questionnaire should take an additional 5-10 minutes to complete.

The purpose of this study is to identify both strengths and difficulties of children 4-7 years of age, without disabilities, who have a biological sibling born with a lifelong disability (example: born blind, born with a chromosomal abnormality, etc). Please note that siblings of children with disabilities from maternal substance abuse are excluded from this study. This study also excludes siblings of children whose only diagnosis is autism as it is not yet known whether autism can ever be diagnosed at birth. If a diagnosis was not detected at or prior to the time of birth, but could have been caught otherwise, the biological sibling may still be included in the study. This study seeks to shed light for counselors of this population so as to aid in the search for strengths at an intake session as well as potential areas for growth. The study uses the Strengths & Difficulties Questionnaire (USA version developed by Robert Goodman in 2005) to gather parent/guardian reports about the functioning of the sibling in five areas: prosocial skills (strengths), conduct problems, emotional problems, hyperactivity-inattention, and peer problems.

First, you will complete the demographic information form, then by the Strengths and Difficulties Questionnaire, and last you will enter your email address in order to receive your \$10.00 gift card from Tango Card as a thank you for your time (limited to first 200 eligible participants, with selections to choose such as Amazon, Best Buy, Home Depot, Starbucks, Target, Wal-Mart, a donation to Special Olympics, and more). You may use any legitimate email address you choose, and you are encouraged to use one by which you would not easily be identified by the researcher or others. Participation in this study is voluntary and will be kept confidential (note: IP addresses are kept to track access and email addresses are kept to send gift cards), and data will be reported in an aggregate form. Your email address will be shared with our gift card partner, Tango Card, through Zapier (the service connecting Survey Monkey and Tango Card). Please note that your individual answers will be viewable to Zapier in order for your email address to be sent to Tango Card. Note there is a minor risk that your information could be accessed, for example by a computer hacker. In order to protect confidentiality, in addition to the above organizations, answers will be stored in secure locations (for example, Dropbox, secured flashdrive/hard drive for backup, password protected computer(s) in locked

office(s)). You do not have to answer any question you do not wish to answer, as you may discontinue participation at any time. If you have the only child in the study / the USA who has a sibling with an extremely rare disorder, others may know you participated when reviewing the list of siblings' disabilities. The questionnaire you are being asked to complete is about the typically developing sibling (non-disabled) who is 4-7 years of age.

Please direct any questions or directions to be excluded from the study to the principal investigator, Joseph Rufus Wofford, via email at wofforjr@email.sc.edu.

By entering information into the following section(s), you are agreeing that you have read and agree to the information indicated above and to have your answers included in the study.

*Do you consent with your personal data being processed as described above? You must click Yes in order to take the survey.

- ☐ Yes
- ☐ No

Demographics form

Child with a lifelong disability diagnosable at or prior to birth:

Age of child with a lifelong disability diagnosable at or prior to birth:

Gender of child with a lifelong disability diagnosable at or prior to birth:

Race/ethnicity of child with a lifelong disability diagnosable at or prior to birth: (Please choose only one.)

Primary diagnosis of child with a lifelong disability diagnosable at or prior to birth:

Typically developing (non-disabled) biological sibling:

Age of typically developing (non-disabled) biological sibling:

Gender of typically developing (non-disabled) biological sibling:

Race/ethnicity of typically developing (non-disabled) biological sibling: (Please choose only one.)

Relationship of typically developing (non-disabled) biological sibling to the child with a lifelong disability:

Informant information

Your relationship to the child born with a lifelong disability:

Your relationship to the typically developing (non-disabled) biological sibling:

What is your age?

What is the highest level of education you have completed?

Which of the following categories best describes your employment status?

Which of the following best describes your current relationship status?

Household information

In what state or U.S. territory do you and the children live at this time?

Total number of children living in the home with you at this time:

Average monthly income for your household from any and all sources, in whole dollars:

Focus for the Strengths and Difficulties Questionnaire

The following page contains the Strengths and Difficulties Questionnaire. The focus for your answers must be only for the typically developing (non-disabled) biological sibling 4-7 years of age.

- ☐ I understand, and I will answer the questionnaire on the next page for the typically developing (non-disabled) biological sibling only.

[Survey software version is slightly different (please see link on first page of this document). Also, on the survey software, questions are blocked in groups of five.]

Strengths and Difficulties Questionnaire
P or T⁴⁻¹⁰

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of the child's behavior over the last six months or this school year.

Child's name Male/Female

Date of birth.....

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless, overactive, cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often complains of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shares readily with other children, for example toys, treats, pencils	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often loses temper	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather solitary, prefers to play alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally well behaved, usually does what adults request	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many worries or often seems worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has at least one good friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often fights with other children or bullies them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often unhappy, depressed or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally liked by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easily distracted, concentration wanders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous or clingy in new situations, easily loses confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often lies or cheats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Picked on or bullied by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often offers to help others (parents, teachers, other children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinks things out before acting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steals from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets along better with adults than with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many fears, easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Good attention span, sees work through to the end	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Signature Date

Parent / Teacher / Other (Please specify):

Thank you very much for your help

© Robert Goodman, 2005

Email address for gift card

Thank you for completing the survey. Please enter the email address below for your gift card (limited to first 200 eligible participants). Your email address will be shared with our gift card partner, Tango Card, through Zapier (the service connecting Survey Monkey and Tango Card). Please check your junk mail folder if you do not receive an email within an hour.

Email address for gift card:

APPENDIX D: LIST OF LOCATIONS AND RECRUITERS FOR THE SURVEY

Places Survey Posted	Date posted
Blog - This little Miggy stayed home	11/17/2017
Club 3-21 private Facebook page	11/18/2017
Key changes therapy services Facebook page	11/18/2017
Elizabeth Kiprotich recruiter	11/18/2017
Updated survey with gift card offer sent to places below	
Family Connection SC - Padgett Mozingo via Sherry Larson	1/28/2018
The Therapy Place - Joye Lee family services coordinator	1/28/2018
Blogger for This little Miggy stayed home	1/28/2018
Upside to down private facebook page	1/28/2018
Club 3-21 private Facebook page	1/28/2018
Owner of Key Changes Therapy Natalie Mullis natalie@keychangestherapy.com	1/28/2018
Occupational Therapist with Therapeeds haylee.mitchell@yahoo.com	1/28/2018
Early Interventionist with Beyond EI brittanykhooks@gmail.com	1/28/2018
Speech therapist with Midlands therapy haskinsa1213@gmail.com	1/28/2018

APPENDIX E: SIGN WITH QUICK RESPONSE (QR) CODE AND DIRECT LINK

Survey Opportunity:

First 200 eligible participants receive
a \$10 gift card same day

Attention parents:

Survey about siblings (4-7 years of age) of children born with lifelong disabilities, first 200 eligible participants will receive a \$10 gift card (with selections to choose such as Amazon, Best Buy, Home Depot, Starbucks, Target, Wal-Mart, a donation to Special Olympics, and more). The demographic data should take about 2-3 minutes to complete and the questionnaire should take about 5-10 minutes to complete, so that is about a dollar a minute :). There are not that many of you out there, so please take the time to participate. More details along with the link below.

Hello,

Counseling families of persons with disabilities has been an interest of mine since 2008, and it deepened even more so after one of my sons was born with Down syndrome in 2013. Currently, I am working on my Ph.D. in Counselor Education and Supervision at the University of South Carolina. I am researching the strengths and difficulties of typically developing siblings of persons born with lifelong disabilities. If you are able to participate, know that you are participating in research which will hopefully have a bearing on the training and education of counselors. In order to participate, a parent must have at least two children, one of whom was born with a lifelong disability diagnosable at or prior to birth, and the other of whom is a typically developing child 4-7 years of age. The parent will complete demographic data and then a questionnaire on the typically developing sibling 4-7 years of age. The demographic data should take about 2-3 minutes to complete and the questionnaire should take about 5-10 minutes to complete. Use the link below or simply scan the QR code with a smartphone if you are viewing this in print:

<https://www.surveymonkey.com/r/SibStrengthsAndDifficulties>



Be well,

Joseph Rufus Wofford, Ph.D. Candidate, MA, LPC, NCC, CCMHC

APPENDIX F: RECORD OF CORRESPONDENCE WITH CDC AND OTHER
ATTEMPTS TO ACCESS 2001 FULL NHIS DATA

(Ascending order)

(Note that using a 32-bit operating system did not work, and the CDC never wrote back.)

JOY, MATTHEW <JOYML@mailbox.sc.edu>

Reply all

Tue 2/27, 11:20 AM

WOFFORD, JOSEPH

Inbox

Rufus,

We set up a 32-bit laptop this morning. I extracted the file on that laptop so that you can try importing into SPSS. Just let me know when you will be around.

Thanks.

Matt

From: WOFFORD, JOSEPH [mailto:wofforjr@email.sc.edu]

Sent: Monday, February 26, 2018 05:34 PM

To: JOY, MATTHEW <JOYML@mailbox.sc.edu>

Subject: 32-bit installation for cdc info

32-bit installation for cdc info

Kind Regards,

J. Rufus Wofford, Ph.D. Candidate, LPC, NCC, CCMHC

“What is to give light must endure burning.”— Viktor E. Frankl

WJ

WOFFORD, JOSEPH

|

Mon 2/26, 5:34 PM

32-bit installation for cdc info

Kind Regards,

J. Rufus Wofford, Ph.D. Candidate, LPC, NCC, CCMHC

"What is to give light must endure burning."— Viktor E. Frankl

2001 NHIS sample child data

OL

ODAHOWSKI, CASSIE L

|

Wed 2/28, 2:00 PM

Hi Dr. Brandt,

I have only used the 2010 and 2015 sample adult files from the NHIS survey. This sounds like an incredibly frustrating problem. I am sorry that I cannot help resolve it.

Thank you,

Cassie Odahowski

Get [Outlook for iOS](#)

From: BRANDT, HEATHER <HMBRAND@mailbox.sc.edu>

Sent: Wednesday, February 28, 2018 1:32:46 PM

To: ODAHOWSKI, CASSIE L

Cc: WOFFORD, JOSEPH

Subject: FW: 2001 NHIS sample child data

Good afternoon, Cassie –

One of the Presidential Fellows – a program I direct in my role as associate dean in the Graduate School – reached out to me about NHIS data. I do not do any work with big data but reached out to several colleagues. Dr. Eberth shared with me that you have used NHIS data previously. I am copying Rufus on this email and have included his original email below. I do not know if you will be able to help, but I am connecting Rufus to you.

Thank you,

Dr. Brandt

Heather M. Brandt, PhD, CHES

University of South Carolina

Arnold School of Public Health:

Associate Professor, Health Promotion, Education, & Behavior, 915 Greene Street, Discovery Building, Columbia SC 29208 | t: 803.576.5649

Graduate School:

Associate Dean for Professional Development, 901 Sumter Street, Byrnes Building, Columbia SC 29208 | t: 803.777.1250

e: hbrandt@sc.edu

From: WOFFORD, JOSEPH [mailto:wofforjr@email.sc.edu]

Sent: Tuesday, February 27, 2018 2:45 PM

To: BRANDT, HEATHER <HMBRAND@mailbox.sc.edu>

Subject: 2001 NHIS sample child data

Hi Dr. Brandt,

Hope you are doing well. A faculty member suggested I check with someone in the school of public health for my question. It's a long shot, but here goes. I am writing to find out if you know of a way to access readable data from the CDC for the 2001 NHIS, sample child data. I have been working with IT in the college of ed and we cannot get it in a readable form using either 64-bit computer instructions nor with the 32-bit option. Something about a problem downloading NHIS files from 1970-2005. It looks straightforward until we actually extract and then open the file. Already called, received response from, and sent screenshots to CDC/NHIS folks but still no dice.

Please advise if you or anyone in school of public health might be savvy on this topic or happen to have an excel/SPSS, or other spreadsheet file copy of it stored somewhere. 2004 sample child data would also work.

Alternatively, if there's any chance you could forward this question to the pf listserv, I'd be so grateful.

Here is the link (again I would need 2001 or 2004 sample child data): <https://www.cdc.gov/nchs/nhis/data-questionnaires-documentation.htm>

Please advise,

Rufus

Sent from my iPhone, which means there's probably typos

SDQ for dissertation

1 +

Y

Youthinmind <youthinmind@gmail.com>

|

Tue 2/27, 8:55 AM

Sorry, Rufus we don't have it.

Best wishes,

Helena Hamilton

YouthinMind

On Tue, Feb 27, 2018 at 2:02 AM, WOFFORD,
JOSEPH <wofforjr@email.sc.edu> wrote:

Greetings,

I hope this email finds you doing well. I attempted to reach out to Karen H. Bourdon, first author for norming data on SDQ in the USA, but I could not find a working email address. As you can see from the email history below, I am a doctoral student at the University of South Carolina and I am using the SDQ in my dissertation. I need the norm data for the USA from NHIS 2001, or even data from 2004 as that is the last time the full version was used, but I am having trouble obtaining it (see explanation further below). If you or your assistant have an SPSS file or even an excel file on hand with the full sample of SDQ data from 2001 that you can send, I would be so grateful if you could send it my way. Or if you have it from 2004, just specify if/when sending it.

Reason for difficulty obtaining data from 2001 or even 2004:

CDC simply has a message indicating that data from 1970-2005 is unable to be properly downloaded onto newer model computers. When I try their workaround saving it as a .zip file with someone from our IT department helping me, the data still do not show up in a readable format when extracted.

Please advise,

J. Rufus Wofford, Ph.D. Candidate, LPC, NCC, CCMHC

“What is to give light must endure burning.”— Viktor E. Frankl

SDQ 2001 norm data?

WJ

WOFFORD, JOSEPH

Reply all|

Mon 2/26, 7:55 PM

kbourdon@mail.nih.gov;

JOY, MATTHEW <JOYML@mailbox.sc.edu>;

GOLD, JOSHUA <JOSGOLD@mailbox.sc.edu>

Sent Items

Greetings Dr. Bourdon,

I hope you are doing well. I am a doctoral student at the University of South Carolina and I am using the SDQ in my dissertation. I need the norm data from NHIS 2001, or even data from 2004 as that is the last time the full version was used, but I am having trouble obtaining it (see explanation further below). If you or your assistant have an SPSS file or even an excel file on hand with the full sample of SDQ data from 2001 that you can send, I would be so grateful if you could send it my way. Or if you have it from 2004, just specify if/when sending it.

Reason for difficulty obtaining data from 2001 or even 2004:

CDC simply has a message indicating that data from 1970-2005 is unable to be properly downloaded onto newer model computers. When I try their workaround saving it as a .zip file with someone from our IT department helping me, the data still do not show up in a readable format when extracted.

Kind Regards,

J. Rufus Wofford, Ph.D. Candidate, LPC, NCC, CCMHC

"What is to give light must endure burning."— Viktor E. Frankl

DHIS_RESPONSE REQUIRED: Topic: nhis, Priority: Medium,
Mode: Email [ref:_00DU0YCBU._500t0821XB:ref]

WJ

WOFFORD, JOSEPH

Reply all|

Wed 10/25/2017, 3:08 PM

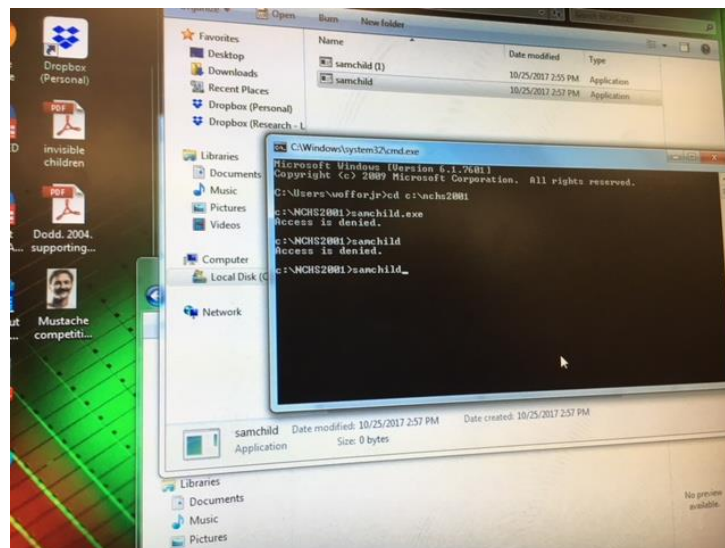
NCHSED (CDC) <nchsed@cdc.gov>

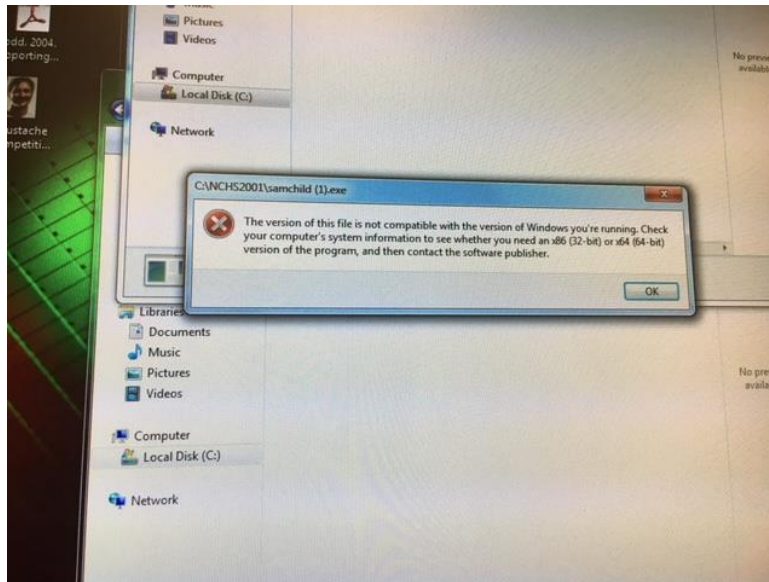
You forwarded this message on 11/16/2017 10:22 AM

Hello,

I have tried this but it does not work with a 32-bit nor a 64-bit Windows 7 operating system. I am with an IT administrator from the University of South Carolina as I write this and we cannot get it to work. Please see attached for reference photographs of failed advanced attempts to run the execution file in a Windows 7 32-bit operating system.

Please advise with troubleshooting information or information on how else I may access the data.





Kind Regards,

J. Rufus Wofford, MA, LPC, NCC, CCMHC

Sent from my iPhone, which means there are probably typos

On Oct 18, 2017, at 4:28 PM, NCHSED (CDC) <nchsed@cdc.gov> wrote:

Good afternoon. Please see the below response from the Division of Health and Interview Statistics.

Dear Data User,

<https://www.cdc.gov/nchs/nhis/data-questionnaires-documentation.htm> on this page you will have to navigate down until you see 2001 NHIS.

Download the sample child data file, which can be found under the Dataset link. The documentation can be found under the Dataset Documentation link. The questionnaires can be found under the Survey Questionnaires link.

You may need the Person File for additional information on these children or other files for your research. Please review the 2001 Survey Description Document for detailed information on merging files if you need these files in conjunction with the Sample Child File.

You should find all of the documents on the website link above.

Sincerely,

National Center for Health Statistics

From: CDC-INFO Response (CDC)
Sent: Tuesday, October 17, 2017 7:32 PM
To: NCHSED (CDC) <nchsed@cdc.gov>
Subject: RESPONSE REQUIRED: Topic: nhis, Priority: Medium, Mode: Email
[ref:_00DU0YCBU._500t0821XB:ref]

Please let us know as soon as possible if your group will provide the answer to the inquiry below or if the inquiry should be referred elsewhere, for example to a state or local health department, another CDC program, or other federal agency. Specific guidance on a referral and contact information would be appreciated.

This inquiry is being escalated because CDC-INFO does not have the information.

Programs are asked to reply within 3 business days of receipt of this escalation. If there is a delay, please let us know when to expect the answer so we can share that information with the inquirer. A reminder will be sent in 8 days; the inquiry will be closed after 10 days.

Questions about this inquiry can be directed to the CDC-INFO Correspondence Team by replying to this e-mail. Please reference the inquiry number below and include the e-mail thread line in your response. The thread line is the e-mail chain including this e-mail and the original e-mail request. To include the thread line, reply to this message without deleting the historical e-mail chain.

Thank you,
R.P.

The privacy of the inquirer should be protected in any transmission or storage of this e-mail.

----- Case Description -----

Joseph Wofford
wofforjr@email.sc.edu
803-206-7346
10/16/17 8:47 AM

Grad Student-Which data do I download to get the strengths and difficulties information?

Caller Comments-NHIS 2001 data set Strengths and Difficulties; The data for 4-7 year olds is 2779 children, 1,321 were female, 1,458 were male; Caller would like to access the data set and narrow down to answers provided for those individuals.

Agent Notes-Call escalated because files were not accessible by agent to assist in searching for data after attempting to se